

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

Introduction:

Multiple myeloma is a big challenge. It is an unusual and complex disease. The diagnosis is not clear and treatment recommendations can vary from doctor to doctor. None of this is too reassuring for a newly diagnosed patient. *However*, with appropriate testing and review a clear diagnosis can be established; patients without symptoms can be monitored without aggressive intervention; patients with symptoms can proceed with therapy 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.

A key component to learning to *live* with myeloma successfully is helping patients and their family and friends cope with their cancer experience by increasing their knowledge, positive attitude, and coping skills. Support is essential to help navigate through the challenges and paths that multiple myeloma can confront a patient and their caregivers. Patient support groups can provide the map and experience: they are designed to provide mutual support and education to members who may feel a little less alone by meeting with others whose situations are similar to their own.

The European Multiple Myeloma Network is a new informal organization of national organizations dedicated to providing the best support services to people living with multiple myeloma and their loved ones. Each participating organization is experienced in forming and sustaining patient support groups. This manual represents a summary of their knowledge and experience.

We offer you this manual with our hope that it provides you the guidance to create your own patient support group in your area. Emotional and social support for people living with multiple myeloma is as important as medical care. The community of support you create 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 Manual

This manual is intended to help you take the first steps if you are considering setting up a support group to help patients living with multiple myeloma and their caregivers. Because the needs and objectives of patient groups vary and the environment varies from country to country, this manual aims to give you some general information to help you decide whether you want to set up such an organization. If you do, it also gives you some specific pointers that will help ensure your success.

Overview

Multiple myeloma, a cancer of the plasma cell, is an as yet incurable but treatable disease. While a myeloma diagnosis can be overwhelming, it is important to remember that there are several promising new therapies that are helping patients live longer, healthier lives.

There are approximately 60,000 people in the Europe living with multiple myeloma and an estimated 21,420 new cases of multiple myeloma are diagnosed each year (European Network of Cancer Registries). Multiple myeloma is the second most prevalent blood cancer after non-Hodgkin's lymphoma. It represents approximately 1% of all cancers and 2% of all cancer deaths.

Diagnosis for the majority of patients is between 65 to 70 years of age; however recent statistics show that the disease is found in patients much younger and at higher rates of occurrence. Because the peak age for multiple myeloma is among the elderly it is thought that susceptibility may increase with aging.

Although a tremendous amount of work has gone into the search for the cause of multiple myeloma, to date no cause for this disease has been identified. However, the search for a cause has suggested possible associations between myeloma and a decline in the immune system, genetic factors, certain occupations, exposure to certain chemicals, exposure to radiation, and, most recently, a virus.

Agricultural occupations, petroleum workers, workers in leather industries, and cosmetologists with exposure to herbicides, insecticides, petroleum products, heavy metals, plastics, and various dusts, including asbestos, seem to have a higher-than-average chance of multiple myeloma. In addition, individuals exposed to large amounts of radiation, such as survivors of the atomic bomb explosions in Japan, have an increased risk for myeloma.

It is important to remember that in most cases, individuals who develop multiple myeloma have no clear risk factors. Myeloma may be the result of several factors acting together.

Why Form a Support Group?

Patient support groups offer people facing multiple myeloma many benefits, each of which contributes to a better quality of life:

- The ability to meet others in similar circumstances
- The opportunity to share methods of coping
- The chance to develop new personal relationships at a time of potential isolation.

Support groups have also been shown to improve patients' adjustment, mood, coping and quality of life.

Other advantages of support groups include exchange of information about myeloma and its treatment and opportunities for mutual problem solving, especially in dealing with the health care system. There are often many cancer support groups that one may join that include participants diagnosed with many different types of cancer. One reason for starting your own support group specifically for patients with multiple myeloma is the mutual support and education achieved by members who may feel a little less alone by meeting with others whose situations are similar to their own.

Before you start

To help get your multiple myeloma support group off to the best possible start, you should find out about local services in your area that may be able to help you. Following are a list of people who may help you be successful. Each may provide you information about starting a patient group, introduce you to other patients interested in starting/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, etc.

Contacts:

- 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.

Note: You can also conduct research on the Internet or visit your local library to get more ideas about best practices that exist for setting up patient groups. In turn, both these resources can provide contact information for the organizations noted above.

Setting up a patient support group

As you think about forming a multiple myeloma patient support group, you may wish to ask yourself:

- 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 yourself spare?
- How much time can the participants spare?
- What are your objectives?
- Will there be any costs?
- Who will organize the group (other than you)?
- Will health professionals be part of the group?

The important thing to remember is that a group starts with you and (at least) one other person. The manual discusses finding members below, but it all starts with you finding that one other person.

Note: Time, energy and the help of “non-patients” may be required to start a support group. They are an invaluable resource in assisting with many of the administrative functions of the group: securing meeting space, handing out flyers, etc. A good starting point to find these key helpers is the friends and family of the myeloma patients.

Aims and Objectives

No two multiple myeloma support groups will be the same. Individual members will determine the aims, goals and activities of each group. Some simply give patients and their caregivers the opportunity to share their stories and experiences. Practical help such as transport to doctors’ offices and hospitals and home visits are often organized. Other groups may be more active in fund raising to press for more research or to help support patient programmes.

At your initial meeting, think carefully about what you want to achieve. Your aims and objectives will drive the sort of things your organization does. For example, if you are an information-oriented group you will need to focus on ways to get your information to patients and caregivers. What you want to achieve will also affect the structure of your organization. If you are setting up an organization aimed at advocating for better services at a local level, you may want to have a local structure. Or if you are setting up an organization aimed at raising money for medical research, you may want to have affiliation with a national group.

Some patient advocacy groups have very broad aims, such as:

“To improve the well-being of people affected by multiple myeloma through information, education and support”

You may prefer to set up an organization that has more focused aims, such as:

“To educate patients and their caregivers about multiple myeloma and its treatment”

“To raise public awareness of multiple myeloma”

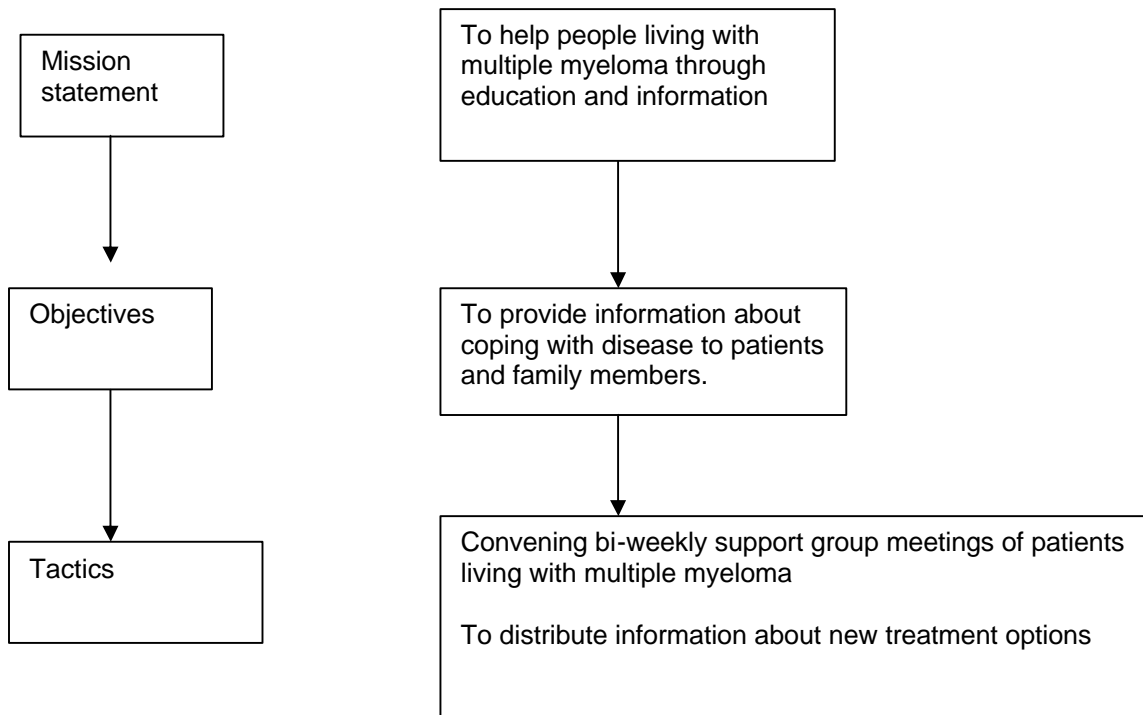
“To press for better services for people affected by multiple myeloma”

Or, you may prefer to concentrate on one area only, such as

“To press for better services for people affected by multiple myeloma”

Whatever you decide, it is important to be very clear about what you plan to do and what your objectives are before taking the first steps.

One way of helping you decide what your aims and objectives are is to try to capture in one or two sentences your mission or purpose. This is your mission statement. Arising from your mission will be your goals or objectives. These will, in turn, give rise to the tactics you use to achieve your goals. (See the diagram below, which gives an example). Remember that over time your mission and objectives may change, so don't worry that you are stuck forever with what you decide at an early meeting.



First steps in setting up your patient support group

A good first step is to hold a meeting with other interested people. Who you invite will depend on the type of organization you plan to set up, but is likely to include patients and their caregivers. The people who attend should share in the commitment to making things better for people affected by multiple myeloma.

General points to consider when running a patient advocacy group:

- Elect a leader --
Details on choosing a leader and a list of their roles and responsibilities follow.
- Start slowly, e.g. monthly meetings --
Once a month will provide the opportunity to build momentum without causing difficulty in carving out time in participants' schedules.
- Get to know each other --
Introduce yourselves, share information about your diagnosis and treatment, provide insight on family and loved ones, and share details on hobbies/interests.
- Share tasks --
Divide and conquer. Have all group members participate by taking on revolving responsibilities that will allow the group to grow and flourish.
- Have an agenda for each meeting --
Provide details on the meeting topics to encourage attendance, allow participants to prepare in advance, and stay focused to ensure the best use of the time spent together.
- Utilize members' skills --
Does someone enjoy baking? Invite them provide the snacks; Does someone love to write? Encourage them to create a newsletter. Is someone a natural leader? Ask them to lead.
- Support members during treatment times --
Offer transportation to medical appointments, offer to run errands, pick up their mail, and walk their dog.
- Share your experiences --
Provide details on lessons learned. A knowledgeable patient is a powerful partner in their healthcare treatment.
- Welcome newcomers --
Encourage existing members to share thumbnail sketches of their treatment and ask 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.
- Offer an inviting environment --
Arrange the seating to foster conversation; provide refreshments; consider playing soft music.
- Meet your members' needs --
Create a mission statement and get group consensus on the objectives; ask for feedback to ensure the group is staying on course.
- Re-assess the group's aims on a regular basis --

Engage the group in discussing the evolving needs and objectives, as new members join, the group grows or shrinks and the needs change.

- Above all please enjoy your meetings!
Have fun. Celebrate life; enjoy the comfort of emotional and social companionship.

Support for your organization

If you want doctors and nurses to direct patients to your organization, it is important to get their support at the outset for what you are doing. Make sure you talk to them when you are planning your organization and ask their views. By engaging them, they are more likely to refer other patients to your support group. They may, for example, pass on a flyer for your group's meeting.

Including the Caregivers

One issue to address early on is that the loved ones, especially the caregivers, feel equal ownership of the group as the people diagnosed with the myeloma. Every family that has a member with myeloma is different. In some cases it's the person with myeloma who is the information seeker. In other cases it's the caregiver. In a few cases it may be more than one family member. Rarely is it the case where there are no information seekers; they don't generally come to support group meetings. Many support group leaders find that it would be a great mistake to focus solely – or even mostly – on people with the myeloma.

Later in your group's development, you may want to consider dividing your organization into subgroups for part of the meeting: those diagnosed with myeloma in one room and caregivers in another. Caregivers often have much to say that they would hesitate to say with their loved one present. The opposite may very well be true, also.

Who is a myeloma caregiver?

A myeloma caregiver is an individual who has a personal connection and commitment to someone with cancer and provides care outside of a hospital setting. With more than 3 million cases of cancer expected to be diagnosed in 2005 in Europe (UICC), at least an equal number of family members or loved ones will be introduced to the extremely challenging role of being a cancer caregiver this year alone.

A day in the life of a caregiver:

In addition to conducting daily tasks, such as preparing meals, cleaning and providing transportation, caregivers virtually become an extension of the care team by frequently talking to health care providers, administering medication and assessing treatment. Unfortunately, this busy schedule often does not leave time for the cancer caregiver to take care of their own needs.

The benefits of caregiver education:

Evidence shows that community-based education and support for caregivers may help relieve the stresses associated with providing care for a loved one with cancer. In fact, caregivers who have participated in support groups have reported significant increases in the degree to which they felt informed about and confident in their ability to provide care.

The Organizational Meeting

Once you've found at least one other person who shares your interest and goals you can start planning the formation of broader group. The next step is to hold at least one organizational meeting. It will usually be quite informal – in somebody's home or over coffee somewhere. After some discussion, you may decide to have your meetings on a particular day and time that will encourage the most people to attend.

By using the resources noted above (in the section “Before you start”) you can find additional people to invite to the meeting. For example you can hang a flyer at a hospital, clinic or doctor offices. The flyer will include information on the purpose of the meeting, the location, the time, the date, and a name and telephone number if they need additional information (see the “Sample materials” section for examples). Or you may find some interested participants by speaking with your physician or local social worker, he/she may know of others who want to initiate a similar group.

Once your organizational meeting is confirmed, remember to create a welcome atmosphere for participants. Following are a list of things to consider:

- Hang signs (if necessary to direct them to the correct location)
- Arrange seating in a circle or another formation that will encourage conversation
- Have name tags for everyone to allow ease in getting to know who everyone is
- Provide a registration sheet to capture contact information for future meetings
- Offer refreshments such as coffee, tea, soft drinks and perhaps some snacks
- Arrange for tablecloths, napkins, other necessary utensils
- Consider playing some soft music in the background

The Meeting Format

Initially you may not have a specific meeting format. It often makes sense to get everyone to introduce himself or herself first. Then as the person who initiated the meeting you may offer a few opening remarks and then invite everyone around the room to tell about their own story. You may wish to create discussion by asking these questions:

- 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?

Once your support group is more established, you can encourage existing members to give a thumbnail sketch of their personal and myeloma history for the benefit of newcomers, and then have the newcomers talk about themselves and their diagnosis and status. You may also want to encourage people to bring family and friends to the meetings and then invite those individuals to share details about their care giving role.

From time to time, the group may be interested in hearing from a guest speaker/presenter. Some examples of speakers, topics and how to find them are as follows:

- Social worker -- provide insights on services offered in the community for completing insurance forms (contact local hospital or cancer clinic)
- Physical therapist -- advice on relaxation or pain relief techniques (contact local hospital or rehabilitation facility)
- Yoga instructor – guidance on how to manage stress (contact local athletic facility)
- Physician – overview of disease (contact local doctor offices)
- Clinical researcher – details on clinical trails (contact local cancer research centre)
- Spiritual leader – benefits of spirituality (contact local church or house of worship)

Choosing a Leader

Somebody has to make sure that meetings happen when they're supposed to, and someone has to lead or facilitate the meeting itself. These don't have to be the same person, and can be rotating duties, but without at least that much organization, the support group can quickly fall apart.

In the early months of a new group, some of the work may have to be done by sheer force of individual personalities. Later, it will become important to ensure that the group will exist beyond the energies of the original founders.

Choose a person, or people, who really want to do the job. Try to find people who will be able to show up on a regular basis. It doesn't take much work to assemble a simple agenda and then let people do what they came for: sharing and learning. As for setting up the meetings, that will take as much or as little effort as is desired. For a meeting in, say, a hospital, it would entail making sure that the room is available, open, and set up with chairs and any other equipment needed. Perhaps it might involve getting some coffee going or bringing some snacks. That's entirely up to the group. In a home or club, that might involve more set-up or even conversion from some previous function to the meeting environment. Again, it's important to find someone, or several people, who really want to do what's necessary.

Roles and Responsibilities - For the Group Leader

The group leader plays a vital role in guiding the group, setting the tone, creating an atmosphere of trust and providing support. These strategies are useful for the group leader:

1. Set the ground rules for attendance, confidentiality and mutual respect for group members. Please note that it is particularly important for support group participants to feel that they can say what's on their minds and in their hearts. For that reason, all participants should know that everything said in the room stays in the room.
2. Ask the group for feedback to help design meeting agendas rather than imposing our own preconceived agenda.
3. Initiate and stimulate discussion, and allow common themes to emerge. You can achieve this by asking leading questions (How did you feel when....? How do you cope with ...? etc), posing topics based on information in the news and actively listening to participants.
4. Take an active part in the group process, especially in creating a safe atmosphere for participation. A safe atmosphere is one where participants do not feel vulnerable, anxious or

threatened. Providing a welcome atmosphere, establishing rules of confidentiality, inviting participants to bring family and friends, and offering encouraging words are key building blocks to a safe atmosphere.

5. Monitor the emotional pulse of the group. When painful topics are being avoided, you may have to introduce them. This can be a very challenging but necessary task. The group as a whole will not succeed if the participants are not able to push themselves to go to the uncomfortable zones. Talking about the painful topics as a group will allow the frustrations, pain, and anger to be released in an atmosphere of emotional support.

6. Reassure everyone that what they are feeling is normal and to be expected. Dealing with cancer as a patient or caregiver is tremendously stressful. Remind everyone they are not alone.

7. Instill hope in the group – share thoughtful quotes; stories of triumph; personal successes or invite a motivational speaker to share their words of encouragement.

8. Encourage networking of group members outside the formal group for additional support and socialization. This might include group lunches, attending a movie or theatre performance, seeing a band, going to a museum, etc.

9. Help members join in the group discussion and involve the more passive members as much as possible. This can be achieved by asking probing questions, providing a topic for discussion and asking everyone for input by going around the room for comments, asking passive members to lead a particular discussion on a topic they are passionate about, etc.

10. Leave sufficient time in the meeting agenda to summarize the process at the end of each group meeting. Perhaps one group member can be assigned the task of timekeeper. They can ensure that each agenda topic receives its portion of time while still ensuring time at the end of the meeting to wrap things up.

11. Provide educational materials, articles and information on issues of concern to the group. These may include disease information pamphlets from a local healthcare facility, brochures on treatment options from pharmaceutical companies, articles on research advances from the newspaper or Internet, as well as materials provided by national myeloma organizations.

12. At some point, it may be appropriate to have the group disband. It could be because members have found other support groups, that the original goals/objectives of the group have been achieved, or because the group lacks the energy to maintain itself. Prepare the group by notifying them of the intention to terminate the group and the do as at the mutually agreed upon date.

Controlling the Meeting

In the case of a group that only meets monthly, an unproductive meeting could easily drive people away who need support. In addition, you may have members who travel a great distance to attend a meeting and they certainly want it to have some substance. Therefore you owe it to the group to maintain some discipline in the dialogue and purpose.

What do most people want in a myeloma support group? Most want a chance to share their experiences, their fears, frustrations, anger, and their victories. They also want to learn from others who have “been there and done that.” They want to ask questions that they've been afraid

to ask their doctor, possibly for fear of sounding silly. They want hope - hope that comes from seeing with their own eyes that multiple myeloma is not a death sentence.

So, what does this mean? It means that the leader needs to carefully control the meeting in order to ensure that the group goals are met. The meeting can easily fly by and it can be difficult to try to ensure that everyone gets a chance to share. This role must be executed delicately and can be very stressful. The good news is that after awhile the group gets the hang of it and doesn't need all that much coaching. How is this done? By practice. An agreed upon agenda will allow for the best use of the time and people will appreciate the structure. A great facilitator who asks probing questions, who does their homework to provide interesting topics of discussion and encourages passive participants to engage will create an atmosphere of energy. Asking members to take turns facilitating will 'train' everyone in the process and encourage the same behaviour at the next meeting. Overtime, the above processes and steps will be what the group is accustomed to and desire. They will in turn help drive the group to meet these goals as much as the leader.

Before and After the Meetings

Regardless of timing of the meetings (once a month; once every two weeks, etc), it can be difficult for members to remember the date for the next meeting. To that end, you may decide to call all of the members several days before each meeting. This not only allows for a necessary reminder, but it allows you to find out the status of treatment, and life in general, for group members and determine their availability to attend the meeting. Then you can provide a report to the group on the well being of any absent members.

Of equal importance to the upcoming meeting reminder is the post-meeting report. It is great to have one member take the meeting minutes that can then serve as a newsletter to members. Some members may only attend infrequently; this newsletter can keep them connected. You want to consider sharing updated membership lists with names, addresses, phone numbers, and e-mail addresses when you distribute the newsletter.

This newsletter need only be a few brief paragraphs noting the topics discussed at the meeting, a list of who was absent and who attended, a introduction of any new members, and maybe even some light-hearted updates such as travel taken, birthdays, new grandchildren, etc. A member of the group might find that drafting the newsletter is a welcome activity – perhaps they are a “frustrated” writer or a former reporter for their school newspaper. The newsletter need only be as informal or formal as the group sees necessary.

Giving your organization a name

It may be helpful to decide what you want to call your organization at a relatively early stage, so you can talk about your organization rather than 'it'. To be successful your organization needs to become known among myeloma patients and their loved ones and using its name is the first step to gaining awareness that it exists.

Will it be a membership organization?

Some organizations have members – individuals or groups who belong to the organization. This is not common in cancer related groups that are normally based on anyone who needs to access the service provided. Unless your group feels otherwise, membership is not required or necessary.

Telling people about your organization

Promoting your organization is something that takes time and energy but your organization will only be able to help the people who know about it. One of your early aims will be to tell as many patients living with mm as you can that it exists. You will need to develop some information about your organization, such as a poster or a leaflet. This should not be too complicated and should set out the main information you want people to have. At a minimum, it should include your purpose and your main aims and objectives. It should also include contact details for the organization.

At the beginning you can use computer-generated flyers that gave the name of the group the location and the dates/times of the next three meetings. Later perhaps one of your members can create a colour brochure or pamphlet and make copies to share. You can use these materials to attract new members. (Sample materials are included at the end of this manual.)

In the event that your meeting times/dates need to be changed, you may want to state on your flyers and brochures that people interested in attending a meeting should call one of your group members to confirm time and date. If your meeting location is always the same, you can include a map to the meeting place on your brochure that makes it easier for people to find you once they decide to attend.

Once you are more established you can develop a web page on the Internet. A member of your group or a friend of one of your members may be internet-proficient and willing to volunteer to make you a web page which will attract and inform more people.

Finances

At the beginning, costs for supporting the group will be minimal. These may include things like tablecloths, coffee, filters, tea, plastic cutlery, cups, sugar, and milk, name-tags, copying costs (for flyers and the newsletters) and of course postage. As your group grows, so will some of our costs, especially the copying and postage. Overtime it will be a good idea for the group to support itself rather than depend on the generosity of a handful of members. The group can vote on how best to achieve this objective such as suggesting a few Euros per family attending. Alternatively, a different member can be responsible for refreshments and setting up each meeting.

Once the group has its own money you will want to look after what there is very carefully. The organization will need its own bank account and it is worth spend a little time finding out which bank will provide the best service to you, at the lowest cost. When you open a bank account for the organization, set it up so you have two people to sign checks this will avoid any arguments.

In order for your organization to grow you will need to find ways to raise additional funds. Fundraising can be done through gaining sponsorship, for example getting a company to pay for

producing and printing a leaflet or booklet. If your organization is based in the hospital, it may have charitable funds to which you can apply. Fundraising events are usually good fun, but you do not to be careful that the cost of the event does not eat up all the profit.

Employing people

Many charities begin by using volunteers to do everything. People who are committed to the cause are willing to give their time to do all the tasks that are needed. However, this usually means that people fit things in during their spare time rather than working solely for the charity.

Meeting space

If you need meetings, you may be able to use rooms at the local hospital or someone may be able to lend you a room to use (even a dining room or kitchen will do).

Data protection

Most countries have some form of healthcare information protection law that prevents the use of a person's healthcare information without their permission. This means that you must ask permission before you keep information on record about people who contact your organization for help. It is worth finding out about any such laws that operate in your country.

Seeking advice

The best way to find out about setting up a support group is to ask for advice from an existing one or from an organization that exists to support patient groups. Most organizations are willing to help people setting up new ones. Members of national multiple myeloma support groups (list of organizations and contact information follows) will be able to give you advice about how their organization operates.

Dealing with setbacks

It is important to acknowledge that all groups are not successful. Groups may fail to effectively 'gel' or unite under the agreed upon mission. This may be due to absenteeism, dropouts or personality conflicts. Some groups may fail because they choose to focus on 'safe' topics such as treatment and anger at the medical system to avoid discussion about their feelings. One way to handle this issue is to use a brainstorming technique to engage the group in discussion. You can do this by simply announcing the difficult topic verbally or by writing the topic on poster board and displaying it for all group members to clearly see. Announce that this will be one of the topics at that day's meeting. You can then offer your perspective on the topic to initiate the dialogue. Remind all participants to speak freely and to refrain from judgment on others remarks. Other than the leader asking for clarity on comments, the participants should drive the discussion. No matter how difficult, each new group should be seen as a learning experience. It's often helpful to discuss sessions with a colleague, friend or family member to keep things in perspective.

Coping with loss

One of the hardest tasks for members of a patient support group is saying goodbye to a partner or friend who dies. However we experience it, grief is the most normal, most appropriate response to loss. 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.

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.

As member of a patient group, there are small ways you can nurture yourself during low spots. You can ask for help from a trusted friend or relative. Remember it's normal to feel overwhelmed at times. You can also find ways to express your feelings. Ignoring feelings just increases their power to come out at times when you may be less able to deal with them. Try to set time aside to focus on your feelings by writing, talking to yourself, or just thinking. Each person has a unique way of coping with loss. The important thing to remember is to grieve in the way that honors who you are.

Guidelines that may help resolve grief

- Allow time to experience thoughts and feelings openly to yourself.
- Acknowledge and accept all feelings, both positive and negative.
- Use a journal to document the healing process.
- Confide in a trusted individual; tell the story of the loss.
- Express feelings openly. Crying offers a release.
- Identify any unfinished business and try to come to a resolution.
- Bereavement groups provide an opportunity to share grief with others who have experienced similar loss.
- If the healing process becomes too overwhelming, seek professional help.

Joining a national organization

You may even want to consider becoming a member of one of the national myeloma organizations. This will give you an excellent opportunity to learn from other support groups across your country and to see the range of activities available from different organizations. One of the most important reasons for joining the national group is that it will give you the opportunity to talk with people who face the same challenges that you do and who share the same aspiration of making this better for people affected by 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
Bürgersteinstrasse 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
Johan Creemers
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
Josef Mayburgerkai 54
A-5020 Salzburg
Phone: +43 664 4250161
sprecherteam@myelom.org
Reimann, Brigitte
Am Wiesbrunnen 27
D-67433 Neustadt an der Weinstraße
Phone: +49 (0)63 21 / 96 38 30
Fax: +49 (0)63 21 / 96 38 31
sprecherteam@myelom.org
Johan Creemers (MM-Patient seit 1997)
Zonneweeldelaan nr. 23 bus 32
B-3600 Genk
Phone: +32 (0)89 / 35 43 66
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
 CH-8123 Ebmatingen
 Tel.: +41 (0) 1/9821212
info@knochenmark.ch
www.knochenmark.ch
- Myelom Kontaktgruppe Schweiz
 Contact via
 Gruppe Zürich
 Heini Zingg
 Löwenstrasse 15
 8400 Winterthur
 Telefon 052 222 47 31
heini.zingg@gmx.ch
 or
 Gruppe Basel
 Ruth Bähler
 Grenzweg 5
 CH-4144 Arlesheim
 Tel.: +41 (0) 61 701 57 19
r.u.baehler@freesurf.ch
 or
 Gruppe St. Gallen
 Rudolf Gamp
 Geerackerweg 24
 CH-8408 Winterthur
 Tel.: +41 (0) 52 222 41 48 or (0) 71 799 18 90
rugamp@swissonline.ch
<http://www.multiples-myelom.ch/>

United Kingdom

- Myeloma UK
Lower Ground Floor
37 York Place
Edinburgh
Scotland
EH1 3HP
Tel.: +44 (0) 131 557 3332
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. They can be helpful in starting groups and can offer back up information and circulate stories about progress made in setting groups up.

Details on support groups are included in their information packs and they can advertise your group in their newsletter and on the Internet via their website (www.myeloma-euronet.org). They can also supply you with a flyer to advertise your meetings in health centres, hospitals and libraries etc.

Table of Sample Materials:

- Meeting flyer
- Meeting agenda
- Greetings letter
- Lost contact letter
- Post-meeting newsletter

Sample Multiple Myeloma Patient Support Group Flyer

INVITATION TO ATTEND

- WHAT** Multiple myeloma patient support group meeting
- PURPOSE** For patients living with multiple myeloma, myeloma survivors and their friends and family to get together for
- mutual support
 - comfort
 - treatment information and
 - friendship
- WHEN** First Saturday of each month from 10 a.m. to noon
Next three meetings:
- 4 January
 - 1 February
 - 1 March
- WHERE** **[Add name of venue and location here]**
See the map on the reverse of this flyer for directions
- CONTACT** If you need additional information, please contact Simon or Anne Baxter at **[insert telephone number]**

We hope that you will join us at these meetings. We myeloma survivors, families and friends can help each other!!!

Sample Multiple Myeloma Patient Support Group Meeting Agenda

Multiple Myeloma Patient Support Group Agenda

Saturday 4 January

10:00 to 12:00

[Insert Venue]

10:00 to 10:30

- Meeting goals
- New member welcome
- Old member introductions

10:30 to 11:15

- Member updates: health, treatment news, personal triumphs

11:15 to 12:00

- Questions and answers about new treatments:

Sample Multiple Myeloma Patient Support Group Greetings and Invitation Letter

[Insert return address]

[Insert Date]

[Insert Address]

Dear [insert name]:

Thank for your inquiring about our multiple myeloma patient support group. We look forward to seeing you along with your family and friends at our next meeting. A schedule of upcoming meetings and events, a copy of our recent newsletter, and a contact sheet for current members are attached for your review.

We believe that our patient support groups can offer people facing multiple myeloma many benefits, each of which contributes to a better quality of life:

- The ability to meet others in similar circumstances
- The opportunity to share methods of coping
- The chance to develop new personal relationships at a time of potential isolation
- The possibility of improving patients' adjustment, mood, and quality of life.

A key component to learning to *live* with myeloma successfully is helping patients and their family and friends cope with cancer by increasing their knowledge, positive attitude, and skills. The objective of our group is to provide mutual support and education to those who may feel a little less alone by meeting with others whose situations are similar to their own.

Our multiple myeloma patient support group was founded in [insert date] by [insert name]. [Insert name] was diagnosed with multiple myeloma in [insert date] and was looking for an informal setting to learn about treatments, hear experiences from other patients, and to share his/her own feelings of fear and frustration. Through his/her leadership, the group has grown to include approximately [insert number] members including patients, and their family members and friends. [Insert name] continues to be an active member of our group along with his/her [insert spouse], but he/she recently passed on leadership responsibility to me. The group has done so much for me by helping to best manage my disease since being diagnosed in [insert date]. I look forward to the new opportunity to give something back to current and future members by serving as group leader.

I have found that emotional and social support is as important as medical care when living each day with cancer. The community of support created by our multiple myeloma patient support group can help all that participate learn to ultimately live life more fully.

Warm regards,
[Insert name]

Sample: Multiple Myeloma Patient Support Group
'Lost Contact' Letter

[Insert return address]

[Insert Date]

[Insert address]

Dear **[insert name]**:

We have missed you at the last **[insert number]** meetings of our multiple myeloma patient support group. You are a valued participant and we miss you.

Perhaps your schedule has gotten busy, preventing you from attending. We appreciate that your personal responsibilities and/or medical treatment may have made it difficult for you. In the event you are finding transportation to the meeting difficult, please let us know as many group members are happy to help arrange for transportation.

As a concerned group of your friends, we are interested to hear how you are doing. Please ring me or send me a note at your earliest convenience.

We look forward to seeing you along with your family and friends at our next meeting.

Warm regards,

[Insert name]

Sample: Multiple Myeloma Patient Support Group Newsletter

(** All names contained within are fictional and are included as examples only.)

Newsletter for the January Meeting

The Myeloma Support Patient Group held its January meeting at the usual time and place. It was surprisingly well attended considering that it was snowing quite heavy. Some of our regulars couldn't attend and they were missed. We had quite a variety of snacks (some actually nutritious) to go with the coffee and iced tea.

This month we had 20 people, including 12 with myeloma. Our meeting facilitator welcomed everyone and did the customary administrative duties.

Member updates:

We learned that **Arthur** and **Alice Smythe** would be going to London next week for a consultation with Dr. Jackson. Arthur recently began treatment with Velcade and will share his experience with us next week.

We heard, too, that **Rob Johnson** went skiing with friends in Switzerland and survived to fly to Paris for a business conference. Bob's wife **Laura** had the good sense to stay in the lodge. Just can't keep that guy down!

Albert Pickford and **Dan Barton** were with us for the first time in a while. Since we saw them last, Danny has been through surgery to remove a tumour from his colon, and Albert has been through very difficult times with his paralysis. He says that the latest speculation is that he has "radiation onset myelopathy" which, everyone hopes, will leave as suddenly as it arrived. In the meantime, Albert has little feeling or control in his legs and is restricted to a wheelchair. They are pretty sure that it is not nerve damage, but involves the spinal cord, perhaps damaged from radiation to a tumour at his T-9 vertebra. It was so good to see them both after a long, though understandable absence.

Wilson and **Carole Reynolds** were back after missing last month. Willie has started Velcade and seemed to tolerate it fairly well. After more than a year of chemotherapy, Willie had a bone marrow biopsy done which showed "minimal residual disease." Willie's oncologist wishes to continue the chemotherapy, however, in hopes of driving the IgG number even lower. That biopsy result was certainly good news for the Reynolds.

Ed Mountain, who consulted with Dr. Jackson as well, has started his new protocol of pulsed Dexamethasone and Aredia. Ed has had a difficult time getting his oncologist and Dr. Jackson onto the same page in his treatment songbook. It sounds like things have settled down for the moment. **Edith** and **Sandra Corcoran** (Ed's daughter and internet helpmate) were also at the meeting.

We had a new couple, **Nancy** and **Roger Quinlan**. Roger was diagnosed as Stage 3 in November of 1996 with what sounds like the light chain variety of myeloma. He had 3 doses of chemotherapy followed by a stem cell harvest and transplant. He took Neupogen to stimulate stem cells. He's had both Groshong and Hickman catheters. He takes Aredia (which helps with pain) as well as Interferon. Roger has a herniated disk in his lower back. His myeloma caused a broken rib and lesions in his spine. Roger and Nancy are delightful people. In spite of all he's been through, Roger has a twinkle in his eye and seems to enjoy life.

Rob Carter came all the way from Manchester. His wife, **Jennifer**, who has the myeloma, was unable to make it this month. We would so like to meet you, Jennifer, so please come to our next meeting. Rob can tell you that we are harmless and loving. Jennifer was diagnosed in December 1996, has had Cytoxan and Prednisone, and has bone pain all over. We urged Rob to help her find the proper people who can figure out exactly what is causing the pain and then find the people who can relieve that pain. Thanks for coming so far to be with us, Rob.

Joe Elliott attended for the first time and his daughter **Jane** was with him. Joe's wife **Kay** was off to London this weekend. Joe was diagnosed in March 1994 with Stage 3 myeloma (light chain). He's had chemotherapy (VAD), but currently only takes Aredia, Velcade, and gamma globulin. Joe had severe involvement all over his body and has lost 5 inches in height from collapsed vertebrae. He's had a laminectomy in his lower back. We will be interested in finding out more about Joe's myeloma journey and hope that he brings his wife with him next month. Jane is hoping for a career in the medical profession and I've challenged her to find us a cure for myeloma - go Jane!

Peter Stockman talked about the reason for this recent trip to see Dr. Jackson in London and the results of the consultation. Peter and Lucy spent three days with the doctor and having tests done. The NTx (bone resorption test) and the PCLI (Plasma Cell Labeling Index test) were both negative, and the two nuclear medicine scans showed a low level of myeloma activity. Because of a new lesion in his left femur, a lesion/plasmacytoma in his skull, and Bence-Jones protein being observed for the first time in his urine, it has been recommended that Peter take 3-6 months of chemotherapy which would start later this month (if his local oncologist agrees). Peter also started Velcade; he will give an update on his experience at next month's meeting.

Administrative Updates:

Having voted last meeting on a contribution toward expenses of € per family at the meetings, we belatedly passed the hat and collected €60. Your faithful facilitator is keeping track of contributions and expenditures for the group.

Just a reminder that next month's meeting will feature a guest speaker – Tim Rubin, a local physical therapist who will present some easy stretches that can promote stress reduction. Thanks to Ed Mountain for inviting Tim to attend the February meeting.

We always miss those of you who are unable to attend, and we look forward to seeing you next month. We are thinking of putting together a luncheon to commemorate the start of spring. How does the April meeting sound to everyone? It would be a “bring a covered dish and all your loved ones” event.

February Birthdays:

Peter Stockman -- 17

Danny Barton -- 23

Closing:

Unfortunately there was not time for everyone to share an update this month. We may, at some point, have to discuss whether or not to expand our meetings. We did not get a chance to hear from **Robert** and **June McDonald** and daughter **Paula**, **Les** and **Jane Parker**, **Bob Carlton**, **Mike** and **Anna Marks**, and **Marcia Bailey**. I can only hope that we didn't miss anything about myeloma that would have benefited the group. I did notice that we had quite a bit of sharing and networking after the meeting was formally closed.

As always, if I have misquoted or left something out, I apologize. No offense is ever intended. You are all very special to me and I welcome contact with any and all of you, whether by phone, in person, or via email. Until February 1st, I remain your friend and fellow MMer,

Catherine Jones