



COMMUNITY PATIENT SUPPORT GROUP GUIDEBOOK

*A resource book to help you form an
independent patient support group in your local
community.*

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Benefits of a Patient Support Group

A patient support group consists of an assembly of people with a similar disease/condition who meet on a regular basis to exchange mutual support and discuss how better to cope with their disease. Attending a patient support group can be one of the initial steps toward accepting and understanding the conditions and effects of kidney disease. There are many benefits associated with developing and participating in a patient support group. A few are highlighted here:

- Support groups provide a place to share common concerns and issues. Individuals who are going through similar experiences can provide encouragement and support to others in the group. This exchange of information and important patient-to-patient collaboration is one of the most valuable elements of participating in a support group.
- Support groups provide valuable information. A renal related support group can provide and share information ranging from kidney disease research, new medications and treatment options. Through participation in support groups, people can take an active role in managing their kidney disease through increasing their knowledge of the latest treatments and techniques.
- Support groups teach coping skills. The information and advice that groups provide can help participants cope with the effects of kidney disease.
- Support groups provide emotional support and reduce feelings of aloneness. Getting together in a group/social atmosphere helps individuals realize they are not alone and provides an opportunity to discuss the initial shock, anger and feelings of helplessness that are commonly associated with being diagnosed with renal failure.

Suggestions for Running a Successful Patient Support Group

Group Philosophy:

A successful patient support group should have a clear mission and purpose for existence. A common thread among many support groups is the desire to help those affected with renal failure to live productive, fulfilling lives despite their chronic illness. This mission can be accomplished by providing individuals an outlet to express their thoughts and frustrations through holding weekly or monthly meetings, and providing patients with the educational tools they need to make the best possible choices for themselves.

Group Composition and Enlisting Help:

Support groups are composed of a variety of individuals consisting of patients, healthcare professionals, social workers family members and friends. Many healthcare professionals in your community are willing and able to help in the process of starting and maintaining a patient support group. Healthcare professionals offer valuable insight and experience in educating patients and bring a different perspective to a support group. You may personally know of nurses, social workers, physicians or psychologists who are experienced in the renal field and are willing to help you recruit members and speak at support group meetings.

In addition to healthcare professionals, attract experienced and active patients in your community to participate in the support group. These individuals will inspire, motivate and teach others through their experiences. Oftentimes, a core group of people emerge as “regulars” at the support group meetings. These “regulars” can become your co-leaders during meetings and assist you with activities relating to the support group. Get these individuals interested by involving them in group planning and helping them to develop skills to deal with issues or problems that may arise during a meeting. With help and experience, they will learn how to facilitate the group and lead meetings in your place.

Location:

Many patient support groups hold meetings in local hospitals, dialysis clinics, churches, libraries, banquet halls, hotels or other community centers. The location of your patient support group meeting might seem like a small task compared to all the other things needing to be considered, however there are a few things to keep in mind.

- Once you choose a location to hold your meetings, continue to use that space. Maximum attendance can be reached by holding your meeting at the same location each time.
- Ensure that support group meetings are easy to find and held in a location that can accommodate the amount of people you expect. If you are having the support group meetings in a hospital or other large area, make sure to specify what floor and room will be utilized.
- Hold the support group meetings at the same date and time. Consider what day of the week is best for members and remain consistent. For instance, meetings might be every other Thursday at 7:00-8:00 p.m. or possibly the 16th of every month. Talk this over with the group and see what works best for everyone.

Attendance for support group meetings fluctuates both in size and in composition. You will find that some people come once or twice, some drift in and out of the group and others attend every meeting. Some meetings will have higher attendance than others, depending upon the topic of discussion, time of year and weather among other factors.

Topics:

Support groups vary almost as much as their individual members. Some groups focus on emotional support; some provide research, treatment and educational information, while others work for awareness. Regardless of the mission of your support group, it is important to have a topic of discussion planned for each meeting. Experienced group leaders have found that attendance tends to be lowest for meetings that have no publicized topic.

Local healthcare professionals and other members of the community possess the ability to provide knowledge on their area of expertise and are a great resource to use for speakers at meetings. The speaker could be a physician, nurse, social worker, dietician, patient or family member depending on the topic to be discussed. It is easy to have every meeting topic fall into the trap of focusing on the negative aspects of renal failure, however, make it a point to keep meetings positive even if the discussion pertains to a serious topic.

Some popular topics for support group meetings are:

- Modality Choices
- Minimizing Problems of Long Term Dialysis
- Going Back to Work
- Coping with the Renal Diet
- Learning How Others Have Successfully Lived with ESRD
- Communicating with Your Physician.
- Programs on Renal Vacations
- Holiday Recipes
- Travel

The AAKP Web site, www.aakp.org, is a great resource for both ideas to use for support group discussions and patient education materials. AAKP HealthLine is a free, one-hour webinar/teleconference program designed to educate individuals on a variety of topics affecting kidney patients and their families. Past programs are archived on the Web site and include topics such as, *Understanding Anemia*, *Understanding Diabetes and Hypertension*, *Meal Planning 101* and *Exercising*. Previous programs, archived on the Web site, can be broadcast and used to supplement a group discussion or in place of a speaker. The AAKP Web site features a comprehensive list of AAKP's educational resources available in a downloadable format for fast, easy reference.

While support groups will not be affiliated with the American Association of Kidney Patients (AAKP), please feel free to use AAKP educational materials publications to supplement information given out or discussed. All educational resources are complimentary and can be ordered through the AAKP Web site, www.aakp.org, or by calling (800) 749-AAKP.

Refreshments:

Providing food at a meeting can promote attendance and provide a welcoming atmosphere. Refreshments are a great way to get people involved and give them a chance to mingle and interact with others. Refreshments should be limited to before and after the meeting so as not to disrupt a speaker or discussion going on during the meeting.

When choosing food items consider the dietary restrictions of attendees and offer a variety of refreshments that are low-fat, sugar-free, caffeinated and decaffeinated. It is also a good idea to provide plates, napkins, spoons and forks, cups and other utensils necessary for serving and eating the refreshments. A good way to get everyone involved is to rotate the responsibility of bringing refreshments or delegate a specific item to each person. As an alternative, explore the possibility of getting a local grocery store or physician's office to "sponsor" meetings and either supply funds to get the refreshments or donate food items.

Food can also be used as a topic of discussion for a support group meeting. As a supplement to the discussion, have each participant bring in their favorite kidney-friendly recipe to share with the rest of the group.

Sharing:

Support groups provide a place to share common concerns and issues. If meetings are primarily lecture style and feature a speaker, allot time at the end for a question and answer period. At times, it may be appropriate for the group leader to facilitate the support group sharing to ensure that everyone is able to speak and given an equal amount of time to express their thoughts and opinions.

While sharing, keep these things in mind:

- Make sure everyone has a chance to speak.
- Never interrupt a person who is speaking.
- Listen to each other.
- Keep an open mind.
- Respect the opinions of others.
- Avoid telling people how to do something, instead offer friendly advice on how you approached or handled a similar situation.

Meeting publicity and community outreach:

One of the most challenging aspects of forming a patient support group is publicizing the location and meeting times to attract members. AAKP has alleviated some of this challenge by providing patients, through its Web site and various publications, a centralized resource to locate support groups in their communities. AAKP will list contact information for independent support groups that are renal related and meet at least once a month in a designated location.

There are many benefits to having a support group listed with AAKP.

- Support group information including statewide locations, contact information for support group leaders and the dates, times and location of meetings will be listed on the AAKP Web site.
- In addition to being listed on the AAKP Web site, support group information will be featured periodically in AAKP's magazines.
- The AAKP Web site will feature helpful hints to assist support groups in their activities, such as how to recruit volunteers, meeting ideas and much more.
- AAKP will provide the support groups with educational materials (as requested) to distribute during meetings.
- Support groups will receive advanced notice of any AAKP events being held in their local communities.
- AAKP will provide up to 10 support groups members with a discounted membership to AAKP.

The Only Actions AAKP Requests in Return

- In order for AAKP to provide accurate, up-to-date information on your support group, we ask you to notify AAKP of any changes to meeting times, location or support group contact person.
- AAKP is happy to supply your support group with educational materials to distribute at meetings and events. To ensure you receive the information in time for your meetings, please allow four weeks for delivery.

In addition to publicizing your support group on the AAKP Web site, create fliers and posters that display the location, date and time of your support group meetings. These should be created two to three weeks prior to the meeting and can be posted at local physician offices, dialysis units, community centers, pharmacies, churches, libraries and any other location in the community that would attract potential attendees.

The following is a list of items that are recommended to be included on the meeting posters and fliers:

- Date and time of the support group meeting
- Location of the meeting and directions if applicable
- Topic of the meeting
- Contact number for more information and to RSVP

Once you have established your support group meetings, word of mouth is very useful. Utilize a “telephone tree,” in which regular attendees are each asked to contact a certain amount of people in advance of a meeting to offer a personal invitation. Have attendees invite family members, friends and other individuals affected with kidney disease to upcoming support group meetings. Once the group gets going with active members, continue to post fliers and posters for upcoming meetings for those individuals that might not have heard about the group yet.

Summary of Guidelines for Starting a Patient Support Group

Support groups for patients dealing with kidney disease are a growing need in many communities. When deciding to start a patient support group in your area, keep in mind these helpful hints.

- Assess the need for a local patient support group in your community. In order to run a successful patient support group there has to be a need fulfilled and interest within the community.
- Once this need has been determined, locate and recruit a group of individuals who are interested in helping to form a support group. These individuals can be patients, healthcare professionals, family members and friends.
 - Decide what your support group hopes to accomplish. This can be as simple as helping patients deal with the affects of kidney disease.
- Brainstorm with your group about where you would like to hold your support group meetings, how often you would like to meet, what time and day of the week.
 - Work with local community centers, dialysis clinics, hospitals and churches to find a central, convenient meeting location that will accommodate your group.

- At this point in time, your group will need to decide an issue or topic of discussion to center your initial meeting around and secure a speaker.
 - A popular topic is diet and nutrition, where a registered dietician can speak to attendees about proper portion sizes and vitamins and minerals that affect kidney patients, such as phosphorus, potassium, sodium etc.
- Once the topic of discussion, date, time, location and speaker are secured, you will need to start publicizing your patient support group meetings.
 - Create fliers and posters detailing your support group meeting and place them in local centers and medical facilities.
 - Enlist your group members to make phone calls to other patients, friends, family members and healthcare professionals to personally invite them to the meeting.
 - Contact local newspapers, daily and non-daily, to place announcements. Research local media outlets in the community for places to post your information at little to no cost.
- At the initial support group meeting serve light refreshments and give an overview of the patient support group to attendees.
 - Following the presentation of the speaker, allow time for attendees to mingle and talk amongst themselves.
 - Make sure to collect the name, address, phone number and email address for each attendee in order to remain in contact and inform them of upcoming meetings.

AAKP hopes that the information provided in this guidebook will assist you in the process of developing and maintaining a successful patient support group. For more information about listing your support group with AAKP, please contact us at (800) 749-2257 or info@aakp.org.