



Support Groups

- For Kidney Patients, Family Members, Caregivers and Interested Individuals

TABLE OF CONTENTS

INTRODUCTION	1
DEVELOPING A KIDNEY DISEASE PROGRAM	2
<i>Establishing a Support Group</i>	3
<i>Marketing the Support Group</i>	4
<i>Planning the Meeting</i>	4
<i>Group Process</i>	5
<i>Evaluations</i>	7
<i>Expected Outcomes</i>	8
RESOURCES	9

INTRODUCTION

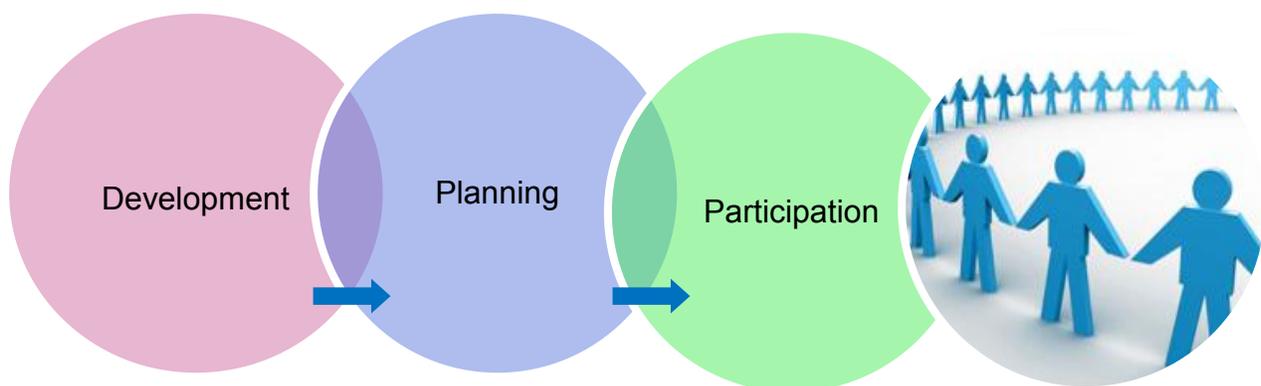
Definition

A support group for kidney patients, family members, caregivers and interested individuals can be defined as a forum, where group members are provided with the opportunity to meet regularly to discuss topics related to kidney disease, share information and experiences, and to provide and receive support. It also helps group members discover they are not alone and that others have the same or similar problems.

Purpose

The purpose of a kidney disease support group is for group members to:

- Receive emotional support in a safe, welcoming environment
- Share thoughts, feelings and concerns
- Learn from one another's knowledge and experience
- Problem solve
- Establish friendships and gain a sense of belonging
- Become educated and informed
- Develop skills needed for personal growth and development



DEVELOPING A KIDNEY DISEASE SUPPORT GROUP

Establishing the Support Group

Organizing and developing a kidney disease support group takes time and effort. The following are some issues to consider in the development of a group:

- **Membership** - Participation is voluntary but it is important to consider and define group membership. A kidney disease support group may be open to all individuals who are diagnosed with or are affected by kidney disease. A targeted kidney disease support group for new patients may be open only to patients who have been diagnosed within the last year. Such a group could be extended to include caregivers as well.
- **Location** - Kidney disease support groups can meet in a variety of settings. It is best to meet regularly in a neutral, community-based setting where group members can be assured privacy.
- **Meeting Day and Time** - Group members can provide suggestions based on their schedule. Sunday is the only day when there is not scheduled in-center hemodialysis which makes it the preferred day for some people. Others prefer to meet during the day or in the evening.

Meetings are usually one to two hours in length. If more time is needed for specific individual issues, the facilitator and interested group member can schedule a mutually acceptable time to discuss the issues further.

- **Cost** - There is no charge for membership.
- **Confidentiality** - All information shared at the group meeting will be kept private and confidential.
- **Leadership** - Kidney support groups will be facilitated by a trained professional and may be co-facilitated by one or two group members.
- **Group Size** - Although group size varies from meeting to meeting, for group members to have the greatest benefit from the group experience, it is recommended that group size not exceed 10-12 members. If the group becomes larger than 12 members, it is recommended that group members and the facilitator consider dividing into two groups.

- **Group Content and Process** - The focus of a kidney support group is to provide members with emotional support, to offer members the opportunity to discuss issues related to kidney disease, and to share thoughts and feelings in a safe, welcoming environment. The facilitator and group members can plan for educational programming to augment and provide balance to the meetings.

GROUP TYPES

Groups can be targeted to:

- A specific age or gender
- Individuals who are coping with an illness
- Family members, friends and interested individuals

Groups can be *open* or *closed*:

- **Open** groups welcome all individuals at any time. Individuals can choose to attend when they have a concern and need to problem solve, when they are in need of emotional support or to attend an education presentation or social event.

Some of the benefits for selecting an “open group” are that the group is designed to be inclusive, enabling new members to share their thoughts, experiences and feelings at a time that is convenient for them and enriching all group members with added insight and support.

- **Closed** groups are for only those individuals who are committed to participating in the group and who have agreed to abide by the group rules developed by the group leaders and group members. Potential members may be screened to determine if they would be appropriate for the group.

The benefit of a “closed group” is that the group is usually smaller and more cohesive. Group members tend to be committed to attending the meetings and to working on goals and personal growth.

Marketing the Support Group

Promotion is an important factor in recruiting group members. Before promoting your group to others, it is important to:

- Create an identity by giving the group a name
- Establish a mission statement (e.g., to provide support, encouragement, education, etc.)
- List the group's services (e.g., meetings, newsletter, etc.)
- Select a contact person and provide contact information (e.g., telephone number, email address, etc.)

Create a flyer or a brochure that can be easily handed out to prospective participants. This information can also be used to make a poster or bulletin board announcement.

To let other know about the group:

- Inform dialysis facility staff of the support group meetings and ask them to identify and encourage appropriate patients to attend.
- Encourage word of mouth recommendations by patients committed to attending the support group.
- Promote general interest by holding an open forum or sponsoring a social event.

Planning the Meeting

- Be organized
- Prepare an agenda. This could include: main topic(s) for meeting, speakers or discussion leaders for each topic, approximate time allotted for each topic and information about next meeting.
- Set up a table with a sign-in sheet for group members. Provide name tags and a schedule of future support group meetings.
- Display educational materials, newsletters, books, Web sites, contact information for renal organizations, governmental agencies, The Renal Network, Inc. and information/flyers on upcoming events.
- Develop a communication system to alert group members if the meeting needs to be canceled.

THE MEETINGS CAN INCLUDE:

- Sign-in
- Welcome/opening
- Introductions
- Review of the agenda
- Reminder about confidentiality
- Review of group rules, such as, no crosstalk, keep discussion as one group, provide positive feedback, no aggressive behavior (cursing, yelling, shouting)
- Topic discussion by invited guest or facilitator
- Members open discussion and sharing related to the specific topic
- Summary of key discussion points
- Plan for the next meeting
- Closing

Group Process

The success of the support group relies on each member of the group understanding the support group process and committing to:

- a. Promote individual participation
- b. Maintain a balance of power and influence
- c. Respect each viewpoint as valuable
- d. Manage differences and avoid conflict

A support group is meant to:

- a. Create a secure, non-judgmental environment
- b. Focus on sharing thoughts and feelings
- c. Provide support, encouragement and motivation
- d. Help each group member to move beyond their current situation to adjust to life as it has changed.

A support group is not meant to:

- a. Substitute health care services
- b. Be a gripe or gossip session
- c. Be an encounter group or therapy session

The following table outlines some of the obstacles which may threaten to limit the success of the support group. For each barrier to participation identified, some possible solutions are suggested.

It is important to remember that problems may occur at any time. A sudden change in group dynamics or a change in a member's schedule may precipitate a sudden rash of issues. Facilitators must be prepared to identify problems and help the group brainstorm solutions at any time in the support group's lifespan.

Barriers to Group Participation	Ways to Promote Group Participation
Lack of commitment/readiness	Design meetings to: <ol style="list-style-type: none"> a. Provide information on relevant topics to members; address member needs and interests first b. Plan creative and fun ways to explore topics (e.g. have a cook off contest as part of a nutrition talk) c. Create an informal and social atmosphere by placing chairs in a circle or around a table d. Offer kidney-friendly refreshments
Transportation	<ol style="list-style-type: none"> a. Choose locations on a bus route b. Hold meetings at the dialysis center c. Schedule meetings before or after treatment d. Encourage car pooling
Scheduling issues	<ol style="list-style-type: none"> a. Have the group meet on Sundays to avoid scheduling conflicts b. Alternate days and time of meetings to accommodate different shifts. c. Offer more than one groups session
Location	Consider other locations close to the majority of the group members such as the dialysis center, library or church.
Confidentiality concerns	<ol style="list-style-type: none"> a. Have group members sign a confidentiality statement. b. Facilitators address this issue and remind group members that everything that is said at the meeting stays at the meeting. c. Allow trust to develop over time.

Inability to communicate	<ol style="list-style-type: none"> a. Facilitators use group leadership and clinical skills. b. With participants reluctant to disclose, help with group processing and building group cohesiveness.
Stigma, labeling	Facilitators address this issue in the group with questions, such as, “How do you feel about coming to the group?” “Is your family supportive?”
Group is not meeting individual or group needs	<ol style="list-style-type: none"> a. Facilitators discuss with the group members their goals for meetings, topics for discussion, individual needs and the group purpose. b. Redefine goals as needed c. Provide opportunity for anonymous feedback d. Refer group members to appropriate resources.

Evaluations

Group members, either through informal discussion or by participating in a needs survey, can provide input to determine:

- Has the group experience been beneficial?
- What has been helpful; what can make the group more effective?
- Is there a need for education or resources on specific topics?
- Has the time, schedule and location been suitable?

Ending the Group

If, for any reason, the group has to end, the facilitator needs to work together with group members to bring closure by addressing unresolved issues, offering a list of resources, and, if appropriate, providing assistance in transitioning group members to another group.

Expected Outcomes

Over the years, support groups have proven to be a successful intervention to help patients cope with a new or existing diagnosis. Support groups have helped patients to:

- Learn more about CKD and how to manage kidney disease
- Adjust to lifestyle changes
- Stay physically active and socially engaged
- Understand that other patients share the same challenges and have successfully overcome them
- Become more engaged in their treatment

Family members and caregivers are also affected by the support group process. Directly or indirectly, family members and caregivers gain knowledge, implemented problem solving techniques, receive support, and gain strength in knowing that they are not alone.

Testimonial “I am not sure I could have achieved as much as I have with my own nutritional therapy without the support group at John Hopkins. A support group can make the difference.”

*Ahlstrom, Timothy P. **The Kidney Patient's Book: New Treatment, New Hope**, page 256. Delran, New Jersey: Great Issues Press, 1991.*

RESOURCES

Suggestions for Group Topics

Quality of Life Issues

- Accepting and adjusting to the CKD diagnosis
- Learning, problem solving, dealing with the disease
- Fitting exercise in your daily routine
- Stress management
- Family relationships
- Sex and intimacy
- Spirituality
- Work issues
- Vocational Rehabilitation

Treatment Choices

- Dialysis – In-center hemodialysis, home hemodialysis, peritoneal, NxStage
- Making the choice for access -- fistula, graft, catheter
- The benefits of fistulas
- Transplantation – Donor choices, medications, rejection, insurance coverage

Care and Treatment

- Medications
- Lab reports and lab values
- Side effects – Leg cramps, shortness of breath, restless leg syndrome
- Living with CKD and heart disease, diabetes, bone disease or other chronic illnesses

End of Life Care

- Advance Directives: Preparing for the future.
- Durable Power of Attorney for Health Care, Living Wills, Do Not Resuscitate Orders
- Choosing palliative care or Hospice

Food and Liquid Choices to Remain Healthy

- The Kidney Diet: Recipes and hints to manage your food intake
- Coping with fluid restrictions

Psycho/Social and Addiction Problems

- Alcohol/drug addiction
- Mental Health Diagnoses
- Depression related to living with CKD
- Coping during the holidays and special family life events

Financial Issues

- Medicare, Medicaid, SSI
- Insurance coverage

Community Resources

- Social Service Agencies
- Food Programs, Transportation, Housing
- The State Board of Health
- The Renal Network, Inc.

Articles

Fadem, Stephen Z. *A Nephrologist as a Cancer Patient Finds Enlightenment in a Support Group* <http://www.ikidney.com/article.php?id=20080118210158>

Spiegel, David, et al. *Effect of Psychosocial treatment on survival of patients with metastatic breast cancer*. *Lancet*. 14.2 (8668):888-891, 1989

Zarit, Steven H. et al. *Working with Families of Dementia Victims: A Treatment Manual*, Los Angeles, UCLA/USC Long-term Care Gerontology Center, 1983

Renal Outreach

The Renal Network patient newsletter contains articles on patient advocacy groups.

Starting a Patient Group is a short article focusing on the benefits of patient groups. http://www.therenalnetwork.org/resources/resources/RO14_3.pdf

Patient Advocacy Groups: They Really Do Work provides examples of how patients' attitudes and behavior can change when they feel they matter and they are part of something important.

http://www.therenalnetwork.org/resources/resources/RO14_3.pdf

Our Support Group at HDD describes a facility support group's goal to educate, promote good health and celebrate life.

http://www.therenalnetwork.org/resources/resources/RO17_2.pdf

Helpful Web Sites

American Self-Help Clearinghouse

This site houses a database with links to over 1,100 national and international online self-help support groups. 800-367-6274

www.selfhelpgroups.org/

HOPEline

This Renal Support Network (RSN) program offers the opportunity for kidney patients and family members to have direct contact with a caring and knowledgeable patient who can share his/her experiences and offer hope. 800-579-1970

<http://www.rsnhope.org/programs/HopeLine.php>

On-Line Support Groups and Discussions

Life Options provides links for dialysis and transplant groups and for groups that focus on many topics that relate to chronic kidney disease. 800-468-7777

<http://www.lifeoptions.org/links/links.php?sect=11>

The Self-Help Resource Center of Greater Toronto

The goal of the center is to provide self-help, increase awareness of community self-help groups and to facilitate the growth and development of self-help groups, networks and resources. The center website has a resource link called *How to Start and Maintain a Self Help Group*, which is translated into five languages. 888-283-8806 (Ontario)

<http://www.selfhelp.on.ca>



The Renal Network, Inc.

ESRD Network 9/10

911 E. 86th Street, Suite 202

Indianapolis, IN 46240-1858

Phone: 317.257.8265

Fax: 317.257.8291

Patient line: 1-800-456-6919

Email at: info@nw10.esrd.net

Web sites:

www.therenalnetwork.org

www.kidneypatientnews.org

Published under CMS contracts

HHSM-500-2006-NW 009C

& HHSM-500-2006-NW 010C