



Support Groups: Where to Begin

For Kidney Patients, Family Members, caregivers
and Interested Individuals



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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:

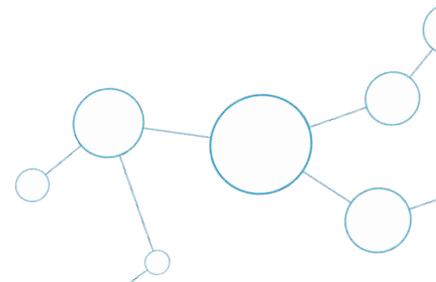
- To discuss topics related to kidney disease
- To share information and experiences
- To provide mutual support and discuss how to better cope with their kidney disease
- To help with accepting and understanding the conditions and effects of kidney disease

A support group can also help 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 Support Group

Establishing the Support Group

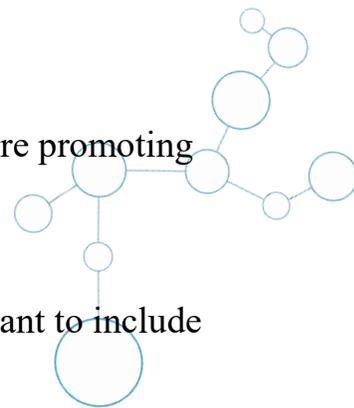
Organizing a kidney disease support group may take time and effort, but both organizers and participants will be rewarded once a support group takes off. Here are some issues to consider as you begin exploring developing a support group:

- **Membership:** most dialysis clinic kidney support groups encourage dialysis patients and their family members or caregivers to participate. You may also want to encourage staff members to attend the meetings to help with discussion as well as to learn of the concerns being expressed by the members. You may also consider sponsoring the support group in collaboration with another dialysis facility, or opening your support group to patients at other clinics.
- **Location:** Kidney disease support groups can meet in a variety of settings. It is best to meet regularly in a community- based setting where group members can be assured privacy. The location should be easy to get to, and have plenty of free parking.
- **Meeting Day and Time:** Group members can give suggestions based on their schedules. Some dialysis patients may prefer to meet during the day to minimize driving at night. You also may want to consider skipping winter months altogether so participants aren't driving in bad weather.
- **Meeting Length:** 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 should be facilitated by a trained professional and may be co-facilitated by one or two group members.

- **Group Content and Process:** The facilitator and group members can plan for educational programming to augment and provide balance to the meetings. Remember it's important periodically to ask your participants for their input on topics they would like to discuss, and/or speakers they might like to hear.

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. Examples of ideas you may want to include in your mission:
 - To provide support, encouragement, education
 - Help people live productive and fulfilling lives despite chronic illness
 - Show patients that they are not alone in their dialysis journey by meeting other people with like problems and concerns
 - Provide an outlet to express thoughts and frustrations for emotional support
 - Provide educational tools to make the best choices for themselves
 - Provide research and treatment information
 - Work for awareness
- List the group's services, such as meetings, newsletter and resources.
- Select a contact person/coordinator for the support group and provide contact information including the coordinator's name, telephone number and email address.
- Consider creating a Facebook page, Twitter account and/or a website dedicated to the support group.
- Set-up a patient line where interested patients can leave voice mail messages. Call-backs can be made by the coordinator or designated helpers to answer questions and recruit members.
- Contact other local organizations which will help get the word out, such as Qsource ESRD Network 10 (ESRDNetwork10@qsource.org), National Kidney Foundation chapter affiliates, AAKP and other patient-focused groups.
- 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 announcements.

Spread the Word

- Contact other dialysis clinics in your area to let them know you're planning to begin a support group. They may be interested to help and to collaborate, or at the very least, provide their patients with the information on your meetings.
- Talk to your 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 meeting at the clinic, a lobby day, or sponsoring a social event.

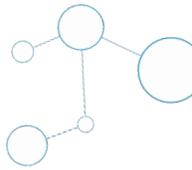
Planning the Meeting

- Set time, place and date for meetings. Post announcements where patients will see them, such as in the lobby, at the scale and at the handwashing sink.
- 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.
- Plan for a registration table at the meeting, with a sign-in sheet for group members. Provide name tags and a schedule of future support group meetings. At registration, collect participants email addresses so you can email future announcements to them.
- Display educational materials, newsletters, books, websites, contact information for renal organizations, governmental agencies, Qsource ESRD Network 10 and information/flyers on upcoming events.
- Develop a communication system to alert group members if the meeting needs to be canceled.
- Extras – you could offer enticements such as refreshments and/or door prizes for participants. If you decide to add these offerings, enlist the help of others to ask for donations from local merchants so the burden won't be totally on the coordinator! Ask the dietitian for help to ensure the snacks are renal-friendly.

Invitation – Elements to Include

- Date and time of the support group meeting
- Location of the meeting and directions if applicable

- *Where participants can park!*
- Topic of the meeting and guest speaker
- Contact number for more information and to RSVP
- If there will be extras – snacks and/or door prizes!



When the Meeting Begins

- 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 - End on a positive note:
 - Share a positive quote
 - Solicit ideas on topics from the participants for future meetings
 - Have members share something they want to celebrate
 - Ask what they learned from the support group session
 - Announce the next support group meeting date and time if it's been established.

Group Process

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

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



A support group is meant to:

- Create a secure, non-judgmental environment
- Focus on sharing thoughts and feelings
- Provide support, encouragement and motivation
- 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:

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



The following table outlines potential obstacles to the success of the support group. For each barrier identified, some possible solutions are suggested.

Barriers to 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.
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 and Follow-Up

Ask group members, either through informal discussion or by a survey:

- 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?
- Ask for ideas on what may make the support group experience more meaningful for the participants.

You may choose to follow-up with participants after each meeting, or perhaps quarterly, to get their perspective on how the group is going and ideas for improvement, as well as for future topics to be covered.

Ending the Group

If, for any reason, the group has to end, the coordinator 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, by helping patients:

- 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.





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

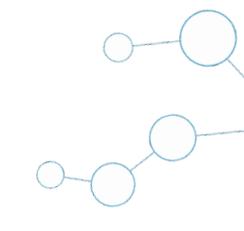
Psycho/Social and Addiction Problems

- 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
 - Qsource ESRD Network 10
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Helpful Websites

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/hopeline-kidney-disease-support-phone-line/>

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.

<https://lifeoptions.org/resource-library/professional-links/>

AAKP

The American Association of Kidney Patients provides links to renal support groups for patients dealing with kidney disease. <https://aakp.org/support-groups/>

Kidney Patient Views Podcast Series

Episode 14: [Empowering Patients Through Support Groups \(Loyola Support Group\)](#)

Episode 13: [Support Groups \(Waukegan Harbor\)](#)

Facebook Groups

Facebook is another source for kidney-specific support group pages. To find the latest, go to Facebook and search Kidney Support Groups.





Qsource ESRD Network 10

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Fax: 317-257-8291

Email: ESRDNetwork10@qsource.org

www.ESRDNetwork10.org

To file a grievance, patients may contact:

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911 E. 86th Street, Suite 202
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