

Facilitating an ESRD Support Group 101

What is a support group?

The Merriam Webster Dictionary defines a support group as “*a group of people with common experiences or concerns who provide emotional and moral support for one another.*” Support groups provide invaluable experience and support to patients, families, and caregivers; they provide hope, education, empowerment, and an outlet in a place where everyone is facing similar challenges.

Why is it difficult to locate a support group?

While the Network receives many phone calls and questions regarding where to find local end stage renal disease (ESRD) (dialysis or kidney transplant) support groups, there don't seem to be many in the community. Why is that? Support groups need local leadership who have the time, vision, and passion to sustain ongoing activities. This can be a significant community barrier. Common patient barriers include a lack of:

- Available transportation.
- Desire to spend any “additional” (non-treatment) time at the dialysis facility.
- Ability/desire to come back to the facility on his/her day “off.”
- Available groups/meetings in the area.

Consider starting your own peer support group if you cannot locate one near you.

How Can You Start a Peer Support Group?

- Start with a small group of people who are dependable and interested in participating in the support group. This group:
 - Does not have to be limited to patients but could also include family members and caregivers.
 - Will be the core leadership who will work on the details of expanding the group.
- Set a day, time, and place for the meeting.
 - Decide the frequency of the meetings (e.g., every other month, once a quarter).
- Locate/arrange a free meeting space to host your support group.
 - Some facilities may allow this onsite.

- Consider talking with staff at a public library, hospital, church, or community center about use of their space.
- Ask your facility if you could post the peer support group flyer/details in the lobby.
- Notify the American Association of Kidney Patients (AAKP) so they can post information about the group on their website’s community support group list.
 - AAKP can be contacted toll-free at 800.749.AAKP (toll free), by email at info@aakp.org, or website <https://aakp.org>.

Any Tips or Best Practices for Running Support Group Meetings?

- Develop and follow rules for the group meetings.
 - For example, no profanity and no complaints about specific facilities or dialysis unit staff members.
- Introduce the meeting topic and have prepared questions to encourage discussion.
 - Plan topics ahead of time and put them on a calendar to save time and allow you to locate speakers and gather educational materials.
- Always end the group on a positive note.
 - Share a positive story or quote.
- Secure guest speakers as far in advance as possible.
 - Guest speakers could include: dialysis/transplant social workers or nurses, renal dietitians, nephrologists (kidney doctors), transplant surgeons, local National Kidney Foundation (NKF) staff, or mental health professionals.
- Consider rotating volunteers (or locate a sponsor) to provide renal-friendly snacks at the meetings.

Try These Additional Resources

- Listen to a 30-minute podcast for inspiration by the Renal Support Network (RSN) about *Starting a Support Group*.
<http://ww.rsnhope.org/patient-experience-success-stories-kidney-talk/starting-a-support-group/>
- Utilize the toll-free **RSN HOPEline** (peer support hotline) at 800.579.1970.
- Utilize the in-depth *Support Group Guidebook* developed by the AAKP.
http://www.esrdnetwork.org/sites/default/files/content/pdf/PCC%20PE/Support_Group_Guidebook_AAKP.pdf