



# END STAGE RENAL DISEASE NETWORK OF TEXAS

## Tips for Increasing Patient and Family Engagement: Patient and Family Group Meetings

### What does Patient and Family Engagement mean to patients?

“Patient Engagement is a patient being completely involved with their team, with the physician, the dietitian, social worker and tech when you’re in-center and being completely involved with everything that goes on as far as the dialysis treatment.”

“Patient Engagement is being able to ask questions about things you’re not familiar with like calcification.”

“Patient Engagement is not being afraid to ask questions. I’m learning that the only dumb question you

have is the one you don’t ask. Don’t be afraid to ask and ask again until you understand.”

#### Feeling Free to Ask Questions



### What are Patient and Family Group Meetings?

**Patient and family group meetings** are regularly scheduled meetings that focus on the needs of patients and their families. At least one patient helps the facility staff plan the meetings. In some instances, such as patient and family group meetings designed to meet the needs of a subset of the population, facilities and patients may collaborate on developing and promoting groups that meet offsite (e.g. a dialysis facility and transplant center collaborate on a transplant support group held at the transplant center). **Plan of Care (PoC) meetings** are focused on the treatment plan of one individual. PoC meetings are NOT the same as patient and family group meetings, where patients and families help plan and conduct the meetings and learn and share together.

Examples of Patient and Family Group Meetings:

- ⇒ Patient Advisory Councils
- ⇒ Support Groups (for patient and/or care partner)
- ⇒ Patient Advocacy Groups
- ⇒ Vocational Rehabilitation Groups
- ⇒ New Patient Adjustment Groups



Involve family members in your groups!

### Special points of interest:

- > What does patient and family engagement mean to patients?
- > What are patient and family groups?
- > How are patient and family groups structured?
- > What type of patient and family group might work best in your facility?
- > Where can I learn more about patient and family groups?

## How are sustainable patient and family group meetings structured?

Asking FPRs and engaged patients to help can save you time and energy.



**“We often forget that patients have lives outside of the dialysis facility.”**

Kidney-friendly snacks draw a crowd!



**1. Patients are involved in planning and promoting the meetings.** Facility Patient Representatives (FPRs) are engaged patients that have accepted a leadership role in a facility. Invite FPRs and other interested patients and family members to help plan the meetings. Utilizing their insight into topics, scheduling, and other important considerations will save you time and energy!

**2. The group’s purpose matches the patients’ needs.** The most successful groups are designed to meet the needs of the individual facility’s patients and families. Ask your FPRs and engaged patients to find out what people would like to know or what they are interested in.

Are some of your patients interested in returning to work? If so, a vocational rehab group might be the best option. Or perhaps your facility would like to increase your ICH-CAHPS scores. A Patient Advisory Council is an excellent way to learn more about the patients’ experience of care in your facility.

Remember that patients’ and families’ needs change over time. Stay in touch with your patients and their families by asking them periodically about their current needs and interests.

**3. Family members are treated... like family!** As renal healthcare professionals, our work with patients is focused on providing treatment. We often forget that patients have lives outside of our facilities and that their loved ones are also heavily impacted by the challenges of kidney disease. Take time to communicate with family members, ask what types of groups they might find helpful, and encourage them to participate. Time invested in your patients’ support system is time well-spent.

**4. Patients and families have an incentive to attend.** Small gestures such as providing refreshments, door prizes, and other giveaways of nominal value can make a big difference in attendance!

**5. Staff and patients have realistic expectations.** Group meetings rarely go exactly as planned. That’s okay! Maybe you didn’t cover the agenda items because questions took the discussion in a different direction. In this case, allow more time at the next meeting for questions and answers.

Perhaps your first meeting only attracted 3 people, even though 12 patients RSVP’d. Think of it this way — three people that you care about got the information and support they

needed. That’s a win, no matter how you look at it! Next time, try an Open House format, or ask an FPR to remind patients the day before the meeting. The most important thing is that you make adjustments along the way, and never stop trying!

**6. Staff members, patients, and families hold each other accountable.** Your patients are watching to see if you will follow through on your commitments to them. If you ask them for input and act on that feedback, they gain confidence in you (and their FPRs). Once trust is established, your patients and/or their families may be more comfortable reaching out for the support they need or bring new ideas to the table.

When you hold each other accountable, you will be able to remind your patients that trust is a two-way street; you expect them, with the support of their families, to self-manage and model healthy behaviors to their peers and participate in healthy patient engagement behaviors inside and outside of the patient and family group meetings. These healthy behaviors improve quality of life for the patients and their families and reduce the amount of time and energy required of the staff.

## What type of Patient and Family Group might work best in my facility?

**Patient and Family Advisory Councils.** Creating an advisory council allows a facility to increase patient satisfaction and safety through timely feedback from patients and their families. Facilities with active patient and family advisory committees experience reduced errors, better health outcomes, and increased patient loyalty.

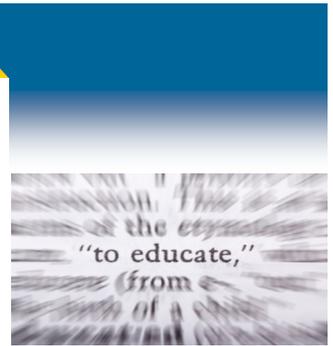
**Support Groups.** Effective support groups promote self-care by addressing the social, emotional, and psychological needs of the patient and/or family. By offering this type of support to patients and/or family members, facilities can improve the health of the entire support system and the quality of life for individuals with kidney disease.

**Patient Advocacy Groups.** Informed patients have the ability to advocate for quality care and improved patient experience of care. Patient advocates can improve communication by serving as intermediaries between patients and staff. Ideally, a facility has an FPR for each shift so that they understand the needs of the patients and staff and are easily accessible.

**Vocational Rehabilitation Groups.** Voc Rehab groups provide support, education, and resources to patients before, during, and after their return to the workforce. Consider this type of group if you have a number of home hemo patients or workforce-age patients. A Rehabilitation Counselor from the local DADS

office can be invited to speak about *Ticket to Work*, which may allow patients to maintain Social Security and Medicare benefits while working. The Rehabilitation Counselor can also provide education on other available programs.

**New Patient Adjustment Groups.** Individuals new to dialysis will benefit greatly from interaction with positive, engaged peers. New patient groups enable patients with high health literacy to coach and/or mentor patients that are new to dialysis. Understanding that individuals with ESRD can continue to enjoy a good quality of life through self-management may encourage new dialysis patients to become engaged in their care.



**Patient and family groups increase health literacy.**

**“Self-care is defined as the actions individuals take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents.”<sup>1</sup>**

## How might staff benefit from patient and family group meetings?

**Group meetings increase health literacy.** Patient and family group meetings not only provide education, but encourage discussion of the material. Discussing the information with their peers may encourage patients to ask ques-

tions and lead to a better understanding of the material better than the traditional instructor-student model.

**Patients learn to self-manage.** Patients with higher health literacy are better prepared to self-manage their dis-

ease. Patients that self-manage require less time and energy from the staff. Healthier patients feel more positive about the level of care they are receiving and have fewer missed appointments due to illness and hospitalization.

**Patients with higher health literacy are better prepared to self-manage ESRD.**





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## Patient and Family Group Resources

### Patient and Family Advisory Councils

- Patient and Family Advisory Councils: A checklist for getting started. Institute for Patient- and Family-Centered Care, [http://www.ipfcc.org/advance/IFCC\\_Advisoryworkplan.pdf](http://www.ipfcc.org/advance/IFCC_Advisoryworkplan.pdf).
- Working With Patient and Families as Advisors: Implementation Handbook. U.S. Department of Health and Human Services' Agency for Healthcare Research and Quality, [http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/Strat1\\_Implement\\_Hndbook\\_508\\_v2.pdf](http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Implement_Hndbook_508_v2.pdf).

### Support Groups

- Meetings/Support Group. Renal Support Network, <http://www.rsnhope.org/meetingssupport-group/>
- Tips to Coping with Chronic Kidney Disease. National Kidney Foundation, [http://www.kidney.org/patients/pdf/ff\\_su05.pdf](http://www.kidney.org/patients/pdf/ff_su05.pdf).

### Patient Advocacy Groups

- American Association of Kidney Patients, <https://www.aakp.org/advocacy.html>
- Dialysis Patient Citizens, <http://www.dialysispatients.org/advocacy>

### Vocational Rehabilitation Groups

- Employment: A Kidney Patient's Guide to Working and Paying for Treatment. Life Options, <http://lifeoptions.org/catalog/>

### New Patient Adjustment Groups

- Peer Mentoring. Network 8, Inc. Patient Engagement Learning and Action Network, <http://www.esrdnetwork8.org/renal-disease-patient-information/patient-assets/LAN-Peer-Mentoring-Fact-Staff.pdf>
- Peer Mentoring. Northwest Renal Network's Patient & Family Engagement Learning and Action Network, <http://www.nwrenalnetwork.org/QI/LAN/PeerMentor.pdf>



**Patients enjoy a higher quality of life when everyone in the family receives the support they need!**



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ESRD Network of Texas, Inc.  
4040 McEwen, Ste. 350  
Dallas, TX 75244  
972-503-3215 Office  
972-503-3219 Fax  
[info@nw14.esrd.net](mailto:info@nw14.esrd.net)  
[www.esrdnetwork.org](http://www.esrdnetwork.org)

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