



END STAGE RENAL DISEASE NETWORK OF TEXAS

Patient Education Campaign 2: Improve Patient- and Family-Centered Care

What does Patient- and Family-Centered Care (PFCC) mean?

If you are a person with kidney disease, or the family or friend of someone with kidney disease, then you know that there are many people on a dialysis Care Team: facility administrators, doctors, nurses, social workers, dietitians, and patient care technicians. A dialysis facility that provides good patient- and family-centered care (PFCC) will put YOU at the **center** of the team, and include you in decisions about your own care!

PFCC is based on four important ideas: respect and dignity, information sharing, participation, and collaboration.



PFCC means YOU are at the center of your care!

Respect and dignity. Your Care Team listens to you and your family and considers your wishes with respect. The staff learns about your values, beliefs, and culture so they can help you make a treatment plan that will fit comfortably into your lifestyle.

Information sharing. Your Care Team shares information with you about your health. When you understand health information, you can help make decisions about your treatment. You and your family will also be able to manage your kidney disease at home because you will understand how to stay strong and healthy.

Participation. Your Care Team will appreciate you taking part in decisions about your care. They will make decisions WITH you, not FOR you or ABOUT you!

Collaboration. You help your Care Team improve care for all of the patients at your dialysis facility! Your Care Team knows that you have ideas that will help other patients feel more comfortable, understand health information better, and make healthier choices.

Patient- and Family-Centered Care (PFCC) means **nothing ABOUT me WITHOUT me!**

Respect and dignity

Information sharing

Participation

Collaboration





Family members and friends have an important role as spokesperson, advocate, and supporter, especially if your loved one or friend, the patient, is too sick or overwhelmed to “speak up” for him or herself.



How can staff, families, and friends work TOGETHER for PFCC?

Talk about your role with your loved one. Ask the patient how he or she would like you to be involved. Attend patient and family group meetings to introduce yourself and learn how you can take part in your loved one’s care.

Observe changes (physical, behavioral, emotional) in the patient and report them to the Care Team. Ask staff what information they would like you to share at each appointment.

Gather helpful information (current medications, medical history, other doctors, and insurance) and help the patient prepare for doctor’s appointments, Plan of Care meetings, and plan ahead for emergencies.

Ensure that you’re there, if possible, at times when information will be shared and decisions need to be made. Put patient and family group meetings and Plan of Care meetings on your schedule. Help your loved one stay healthy by learning about diet, medication, and treatment choices.

Tell staff if you have any concerns about the patient’s health or safety or if you are uncomfortable because “something just doesn’t feel right.”

Help with making decisions about care and treatment. Be a second set of eyes and ears for the patient. At patient and family group meetings, ask questions and take notes. Encourage your loved one to take part in making decisions.

Enlist help from staff members that you are comfortable with so that they can support you and your loved one as you take part in making decisions.

Ready yourself for any changes in your loved one’s Plan of Care. Make sure the patient’s questions have been answered. Make a list of items the patient will need to enjoy the best health possible (medications, supplies, follow-up appointments).

Material adapted from *Better Together Pocket Guide for Families*, Institute for Patient- and Family-Centered Care, www.ipfcc.org.

How can staff PARTNER with patients to promote PFCC?

Patients, families, and care partners are important members of the Care Team. Taking part in patient and family group meetings at the dialysis facility is one way to teach patients and their families ways to manage end stage renal disease (ESRD).

Engaged patients are willing to take the steps necessary to manage their health, while engaged family members provide comfort and help and can speak for patients.

To PARTNER with you and your loved ones, dialysis staff should:

Present themselves to the patient and care partner and explain that you will all be working TOGETHER as a team and that everyone's roles and ideas are important.

Ask the patient and the care partner how they want to take part in making decisions. Teach them about their choices during patient and family group meetings.

Reassure care partners that their knowledge is useful because they know the patient the best. Remind patients and care partners that understanding and following the Plan of Care will improve safety and quality of life for the whole family.

Trust that everyone on the Care Team shares the same goal—the best care for the patient.

Nurture the relationship with the patient and care partner and ask them what topics they are interested in learning more about. Talk about those topics during patient and family group meetings to help them understand how to manage ESRD.

Encourage patient and care partner involvement in all parts of care, from attending group meetings to making decisions.

Review and agree upon the Plan of Care with the patient and care partner so that their wishes are followed.

Support care partners in becoming comfortable in their roles as team members. Provide them with information on how to stay healthy by caring for themselves, as well as their loved ones on dialysis.

Material adapted from *Better Together Pocket Guide for Staff*, Institute for Patient- and Family-Centered Care, www.ipfcc.org.



Staff should encourage the involvement of the patients and care partners, especially when decisions have to be made.





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Patient and Family Group Meetings at My Facility

My facility offers the following group(s):

The next patient and family group meeting will be held:

Group name: _____

Date: _____

Time: _____

Location: _____

For more information, please contact:

Staff facilitator: _____

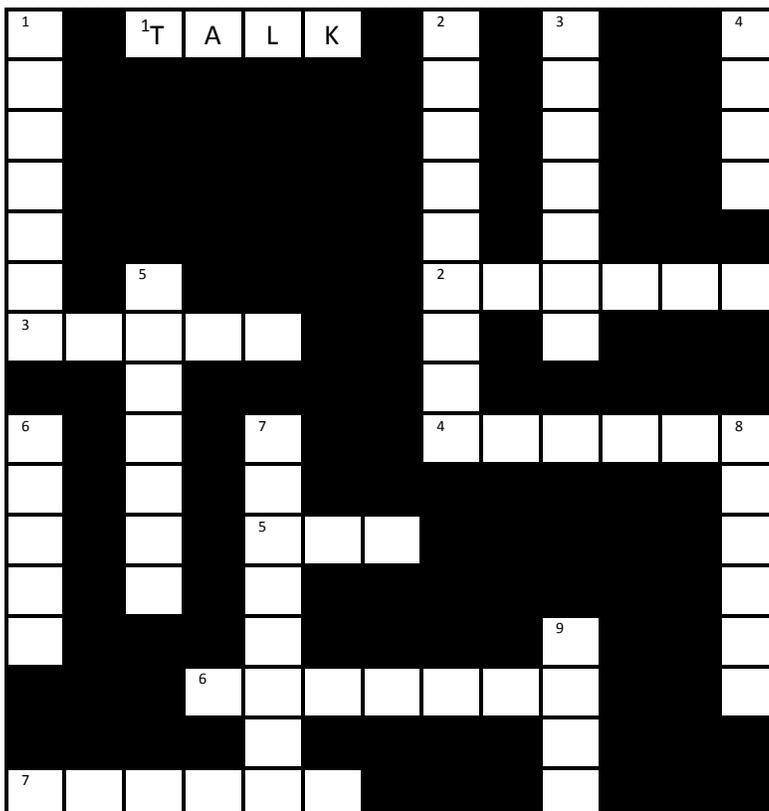
Facility Patient Representative (FPR) MWF: _____

Facility Patient Representative (FPR) TTS: _____

This material was developed by the Network #14 2014 Patient Engagement Learning and Action Network (PE LAN).

ESRD Network of Texas, Inc.
4040 McEwen, Ste. 350
Dallas, TX 75244
972-503-3215 Office
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To file a grievance, please contact the ESRD Network of Texas, Inc., at 877-886-4435, info@nw14.esrd.net, 4040 McEwen, Ste. 350, Dallas, TX 75244, or <http://www.esrdnetwork.org/>.



Use the information on pages 2-3 to answer the clues!

Down

1. Staff should _____ themselves to the patient and care partner
2. Staff should _____ patient and care partner involvement
3. _____ changes
4. _____ staff
5. Staff should _____ care partners as team members
6. _____ yourself
7. Staff should _____ care partners that their knowledge is useful
8. _____ help
9. _____ with making decisions

Across

1. Talk about your role
2. Staff should _____ and agree upon care plans with patients and care partners
3. Staff should _____ that everyone involved shares the same goal
4. _____ that you're there
5. Staff should _____ patients and care partners how they want to take part
6. Staff should _____ the relationship with the patients and care partners
7. _____ helpful information