



# END STAGE RENAL DISEASE NETWORK OF TEXAS

## Patient and Family Group Meetings: Improve Your Quality of Life

### What does Quality of Life mean to me?<sup>1</sup>

Are you living well? . . . really living? Or are you simply surviving, letting the disease make you a couch potato? What is your **Quality of Life (QOL)**? Do you have fun, smile or laugh a lot, enjoy life, feel you are accomplishing something? Do you have a full and satisfying life . . . with family, friends, travel, hobbies, volunteer work?

If you are not participating in the activities that once brought you joy, then your QOL may be low!

While Quality of Care (QOC) is about the medical and self-management of your kidney disease, QOL is about your attitude and how you spend your time when you are not receiving treatments.

Demand more from yourself than just surviving. You need to enjoy an acceptable level of daily living, a new lifestyle. Ask yourself what things are important to you? What keeps you going? What activities did you enjoy before renal failure?

One important way to improve QOL is by participating in patient and family group meetings.

Please read this patient education handout and complete the activities.

**If you have questions, please ask a trusted Facility Patient Representative (FPR) or staff member about participating in patient and family group meetings at your facility!**

### Special points of interest:

- > What does Quality of Life (QOL) mean for people on dialysis?
- > QOL Word Search and Word Scramble Puzzles
- > How can patients and families benefit by attending group meetings?
- > Types of patient and family groups
- > When is the next patient and family group meeting at my facility?

**“QOL is about your attitude and how you spend your time.”**

### People with a high Quality of Life (QOL) often feel:

- Accepting
- Appreciative
- Cheerful
- Competent
- Confident
- Considerate
- Courageous
- Courteous
- Energetic
- Enthusiastic
- Excited
- Friendly
- Growing
- Helpful
- Hopeful
- Optimistic
- Patient
- Peaceful
- Productive
- Relaxed
- Sincere
- Understanding

### QOL Word Search

L C T L Z W A R M S U O E T R U O C L L  
 U B O E E C O U R A G E O U S K P L P J  
 F B P N Y E W P T Y B F W E M I U X E P  
 P H R U L D E T I C X E V V P F O Y S Y  
 L D O Y G D F C O N S I D E R A T E C H  
 E G D T J N Q O O P T B T E L R D K O A  
 H N U N H I L B U A D R E Z U H F Z N P  
 J I C E P K W X I O R H D N M S S K F P  
 Q T T I H N U C P F C G D N E J O J I Y  
 Q P I T T W E T W T Z E X C W M B L D Y  
 C E V A V R I J L B R Q U D B H O W E Q  
 T C E P P M Q U G S P R B M P P W A N E  
 E C T P I J F N T R E L A X E D M K T U  
 S A A S M E I A T V T A E H K P A C U Z  
 H Y T E C W N E N T H U S I A S T I C S  
 O I M A O D T Z N R T T N E T E P M O C  
 C P E R I B V X C K H C L U F E P O H T  
 E P G N M U V H E N E R G E T I C U F H  
 E F G S I N C E R E J T B B M K J M T K  
 E I L W Q Z D Y L F R I E N D L Y A S M



## Types of patient and family groups

**Patient and Family Advisory Councils.** A patient and family advisory council increases patient satisfaction and safety by asking patients and their families to share their ideas about how to improve care. Patients and families are the experts on what they need in order to feel safe and comfortable in a facility!

**Support Groups.** Support groups encourage patients to self-manage their disease. People learn to manage ESRD by learning new information, sharing their experiences with other dialysis patients and families, and enjoying the support of people that understand exactly what they are going through.

**Patient Groups.** People with ESRD can join a patient advocacy group to help promote quality dialysis care. Advocates often represent their fellow kidney patients and families and help bring important issues to the attention of staff members. Facility Patient Representatives (FPRs) also advocate for patient rights in dialysis facilities.

**Vocational Rehabilitation Groups.** For patients that would like to work while on dialysis, vocational rehabilitation (or Voc Rehab) groups can help. Voc Rehab groups offer information and support to patients before, during, and after they return to the workforce. For example, the group facilitator can invite a

Rehabilitation Counselor from the local Department of Aging and Disability Services (DADS) office to speak about the *Ticket to Work* program, which may help some ESRD patients keep Social Security and Medicare benefits while working.

**New Patient Adjustment Groups.** A new diagnosis of ESRD can be overwhelming! New patient groups help connect people that are new to dialysis with positive, experienced ESRD patients and their families. More experienced patients serve as mentors and encourage new patients and families to enjoy a good quality of life by becoming engaged in their own dialysis care.



**People with a high QOL often enjoy the activities hidden in this Word Search!**

- Adventure
- Art
- Career
- Kids
- Crafts
- Education
- Family
- Fun
- Hobbies
- Music
- Pets
- Sports
- Theatre
- Travel

X S T R O P S L L B  
 C E P E C U R A X C  
 A R B L D P F A M N  
 R U Y W C C K R S L  
 E T T I N U F E B P  
 E N S Z T K I O T H  
 R E W E P B W S N O  
 J V J D B B A F L T  
 W D B O E S E R Q O  
 X A H A Q F K H T G  
 Y S H B A F B U W R  
 B J E M E H O O B A  
 J F I C N J J Q F P  
 D L N M N E V T H H  
 Y O O Y N R O J M Y  
 E V I Y A T C N K K  
 Q X T V B A M I F Q  
 B D A C N E C W Q V  
 E W C D A H I O S Y  
 J I U B I T S J T O  
 T V D D J P U T F O  
 N F E O Q X M Q A Q  
 P O N S K T Z A R M  
 D T L N F F P N C Q  
 P R I V Q U N R X A  
 R A K G I B H F O N  
 Q V D M C T C U M S  
 U E V S T E P M Q O  
 D L N V C O O A N X  
 R S D I K I S H X P

### Page 1 Solution

L C T L Z W A R M S U O E T R U O C L L  
 U B O E E C O U R A G E O U S K P L P J  
 F B P N Y E W P T Y B F W E M I U X E P  
 P H R U L D E T I C X E V V P F O Y S Y  
 L D O Y G D F C O N S I D E R A T E C H  
 E G D T J N Q O O P T B T E L R D K O A  
 H N U N H I L B U A D R E Z U H F Z N P  
 J I C E P K W X I O R H D N M S S K F P  
 Q T T I H N U C P F C G D N E J O J I Y  
 Q P I T T W E T W T Z E X C W M B L D Y  
 C E V A V R I J L B R Q U D B H O W E Q  
 T C E P P M Q U G S P R B M P P W A N E  
 E C T P I J F N T R E L A X E D M K T U  
 S A A S M E I A T V T A E H K P A C U Z  
 H Y T E C W N E N T H U S I A S T I C S  
 O I M A O D T Z N R T T N E T E P M O C  
 C P E R I B V X C K H C L U F E P O H T  
 E P G N M U V H E N E R G E T I C U F H  
 E F G S I N C E R E J T B B M K J M T K  
 E I L W Q Z D Y L F R I E N D L Y A S M





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Page 3 Solution

## 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: \_\_\_\_\_

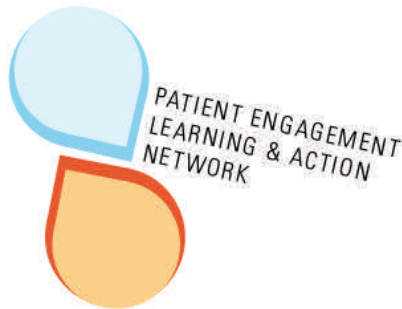
Facility Patient Representative (FPR) MWF: \_\_\_\_\_

Facility Patient Representative (FPR) TTS: \_\_\_\_\_

X S T R O P S L L B  
 C E P E C U R A X C  
 A R B L D P F A M N  
 R U Y W C C K R S L  
 E T T I N U F E B P  
 E N S Z T K I O T H  
 R E W E P B W S N O  
 J V J D B B A F L T  
 W D B O E S E R Q O  
 X A H A Q F K H T G  
 Y S H B A F B U W R  
 B J E M E H O O B A  
 J F I C N J J Q F P  
 D L N M N E V T H H  
 Y O O Y N R O J M Y  
 E V I Y A T C N K K  
 Q X T V B A M I F Q  
 B D A C N E C W Q V  
 E W C D A H I O S Y  
 J I U B I T S J T O  
 T V D D J P U T F O  
 N F E O Q X M Q A Q  
 P O N S K T Z A R M  
 D T L N F F P N C Q  
 P R I V Q U N R X A  
 R A K G I B H F O N  
 Q V D M C T C U M S  
 U E V S T E P M Q O  
 D L N V C O O A N X  
 R S D I K I S H X P

Page 2 Solution

- |               |                 |
|---------------|-----------------|
| Advice        | Motivation      |
| Communication | Refreshments    |
| Coping        | Respect         |
| Education     | Sharing         |
| Encouragement | Support         |
| Friendship    | Understanding   |
| Help          | Quality of Life |
| Inspiration   |                 |



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1. Material adapted from *Quality of Life*, courtesy of The Renal Network, <http://www.kidneypatientnews.org/resources/resources/qolbro.pdf>
2. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Pat Educ Couns* 2002;48:177-87.

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