



Living with Chronic Kidney Disease: The Ups, Downs, and All Arouns

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Thank you to our speaker!



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- Assistant Professor, University of Georgia School of Social Work
- Seminar chair for Georgia Council of Nephrology Social Workers (CNSW)

Objectives

1. Define quality of life;
2. Describe emotional and social aspects of living with chronic kidney disease; and
3. Discuss resources to manage psychological health.

Quality of Life

- Quality of life is a broad concept that reflects an individual's rating of his or her general well-being.
- General well-being is affected by one's **physical health, emotional health, mental health, and social connectedness.**

Burden on Physical Health

- Gets in the way of daily living
 - Caring for yourself
 - Driving
 - Cleaning
 - Housework
 - Shopping
 - Preparing meals
 - Managing medications
- How often are you pain free?
- How often do you feel weak?
- How well are you eating and sleeping?
- Are you able to engage in physical activity?

Common Feelings and Emotions

- Anger
- Frustration
- Sadness
- Fear
- Worry



Depression: Signs and Symptoms

- Sadness
- Emptiness
- Hopelessness
- Irritability
- Difficulty concentrating
- Loss of interest in activities
- Changes in eating and sleeping habits
- Aches, pains, digestive problems



Depression: A Serious Condition

- Affects an estimated 20-30% of the chronic kidney disease population
- Depression is treatable
- If untreated, depression can lead to difficulties in living well with chronic kidney disease



Anxiety: Signs and Symptoms

- Restlessness
- “On edge”
- Easily fatigued
- Irritability
- Difficulty controlling worry
- Sleep problems
- Muscle tension



Grief and Loss

- Persons with chronic kidney disease may experience multiple losses
 - Loss of your kidneys
 - Loss of employment/financial loss
 - Loss of independence
 - Loss of freedom in making choices about your diet
 - Loss of functioning
 - Loss of a life role

Social Connectedness

- The level and quality of interactions we have with people in our social networks
- Primary social supports: friends, family members, caregivers, neighbors
- Secondary social supports: clubs, organizations, places of employment
- Instrumental support: transportation, household chores
- Emotional support: discuss private matters, express empathy

Caregiving

- Caregivers spend an average 24 hours a week providing care
- Caregivers are at risk for emotional distress and health burden
- Caregivers often neglect their own health
- Caregiver self-care: activities you perform to stay well as a caregiver



Poll Question #1

- How would you rate your overall quality of life?
 1. Excellent
 2. Very good
 3. Good
 4. Fair
 5. Poor

Poll Question #2

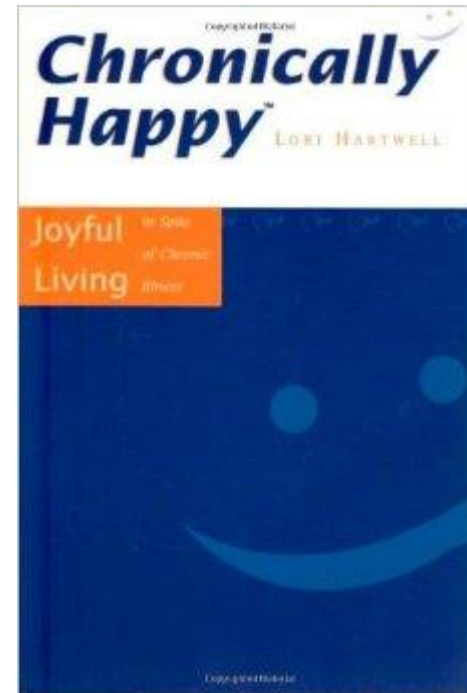
- Is your quality of life rating where you want it to be?
 1. Yes
 2. No



The Ups: Resources, Tips, and Techniques

But first...

- Excerpt from
Chronically Happy
by Lori Hartwell



The Interdisciplinary Treatment Team

- The interdisciplinary treatment team consists of health professionals with expertise in chronic kidney disease.
- Nephrologist
- Nurse
- Social worker
- Dietitian
- Patient care technician
- Transplant surgeon
- Transplant coordinator
- Financial counselor
- Pharmacist
- Psychologist



Nephrologist

- The “kidney doctor” who designs your medical treatment plan
- Monitors your kidney functioning



Dietitian

- Specializes in kidney nutrition
- Provides recommendations for a “kidney diet”
- Meal preparation demonstrations



Nurse

- Coordinates your overall care
- Oversees your treatment
- Provides training on various treatment procedures



Social Worker

- Responsive to your emotional and social needs
- Provides counseling, case management, crisis intervention
- Helps you reach and maintain your desired quality of life



Preparing a List of Questions

- Prepare before medical appointments or your care plan meeting
- Use open-ended questions
- Example:
 - “Am I a candidate for a transplant?” vs. “How can I become a candidate for a transplant?”

Problem Resolution Steps

1. Identify the problem
2. Brainstorm possible resolutions
3. Choose a resolution
4. Implement your selection
5. Evaluate your results

Physical Activity

- Any body movement that works your muscles and requires more energy than resting
- Examples: walking, running, dancing, swimming, cleaning, and gardening



Goal-Setting

- “SMART” goals: specific, measurable, achievable, realistic, and time-oriented
- “I am going to do more physical activity.” vs. “I am going to plant flowers in my garden on my days off from dialysis, Tuesdays and Thursdays, at 10:00 a.m. for 30 minutes.”
- Write it down and post it in a visible location!

Mindfulness Exercises

- Mindfulness exercises help us to relax
- Reduce stress and anxiety
- Can be performed throughout the day in small chunks of time



Mindfulness Exercise: A Demonstration

- Simple breathing exercise
- Developed by Trasie Adams Topple, LISW, PhD
Candidate at the University of Georgia School of
Social Work

Support Groups

- Peer support
- Shared experience
- Learn new ways to cope



Health Education Groups

- Learn about health topics related to diet, medication management, exercise, etc.
- Learn new skills
- Example: Chronic Disease Self-Management Program



Journaling

- Write about your experience
- Celebrate your accomplishments through writing
- Keep track of your feelings and emotions
- Engage in self-reflection

Resources for Caregivers

- Caregiver support groups
- Respite
- Caregiver self-care
- Education



Poll Question #3

- Which resources, tips, or techniques are you most likely to use moving forward?
 1. Utilize the treatment team/prepare questions in advance
 2. Problem-resolution and goal-setting
 3. Physical activity
 4. Mindfulness and journaling
 5. Support groups or health education groups

Summary Points

1. Determine your goal for your quality of life.
2. Depression is a treatable condition.
3. You are at the center of the treatment team.
4. Caregiver self-care is important.
5. Decide what works for you.



Remember, the roller coaster eventually makes its way back to the station where you can exit peacefully.

Thank You

(Disclaimer: Photos were retrieved from publically accessible websites or the AKF website.)

Join us for next month's webinar!

What CAN I eat? Nutrition for Dialysis Patients



Janeen Leon, MS, RDN, LD

Clinical dietitian, researcher, and program evaluator
at the MetroHealth Medical Center
Adjunct Instructor of Medicine at the Case Western
Reserve University School of Medicine

June 14, 2016

1:00 – 2:00 PM (Eastern Time)

Participants in this webinar will:

1. Determine how much protein is required and how to meet these protein requirements
2. Understand the differences between phosphorus and potassium and learn appropriate food sources of each
3. Learn how to manage fluid balance through careful sodium (salt) and fluid use

Go to www.KidneyFund.org/webinars to learn more and register!