Headline News

Changes for Quality
by Kathe LeBeau, weKAN Project Manager, PEPP Speaker

Do you care about the quality of the medical care you receive? Of course you do! A long-awaited revision recently issued by the Centers for Medicare & Medicaid Services (CMS) outlines changes in the regulations governing the operation of U.S. dialysis facilities. These changes will affect your care and your health.

On April 3, 2008, CMS released the final rule for the Conditions for Coverage for the Medicare End-Stage Renal Disease (ESRD) program. Set to go into effect on October 14, 2008, these regulations and guidelines are part of the Medicare survey process and serve as the minimum standards that dialysis facilities must meet to be certified under the Medicare program. In other words, they protect our health and our safety as dialysis patients.

The ESRD Conditions for Coverage have not been comprehensively

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It’s Your Turn

Wow! I Feel Good!
by Mandy Newberry, MEd

It’s a sunny day in Charlotte-tesville. Here on the grounds of the University of Virginia (UVA) Medical Center, the sidewalks are bustling with people as cars line up to drop loved ones off in front of a large brick building. People from all walks of life are making their way to the fifth floor, some unassisted, some with a cane, and some in wheelchairs or even on stretchers.

These people are as unique as they come. Some are parents, some work full time, and others enjoy spending afternoons in a rocking chair on their front porch. But three times a week they share a common bond.

On the fifth floor of that old brick building is the UVA Kidney Center. These people are arriving for their dialysis treatment. But that’s not all. They also participate in the Sit-Fit Exercise Program each time they receive dialysis.

Before you skip to the next article because I said the ‘E’ word, hold your horses! These patients say that the exercise they do keeps them feeling good, despite the exhaustive and sometimes painful side effects of dialysis.

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I see so many doctors, take so many meds, and have a gazillion health issues to stay current on that it makes me feel like my brain needs a memory upgrade. Sometimes my mind is so cluttered with the daily difficulties of kidney disease that it’s important to step back and clear my head.

Using mind techniques shifts my thoughts away from the frustration, fear, and anxiety that can go hand-in-hand with living with kidney disease. Visualization is one tool I use to gain some control.

One of my favorite visualization techniques comes from Wayne Dyer, PhD, a psychotherapist, author, and motivational speaker. He suggests the following exercise, which I’ve paraphrased for simplicity:

**Picture a digital basketball scoreboard.** Once you have a strong visual of the scoreboard, picture a score of 24. Slowly visualize the scoreboard counting backward: 24, 23, 22, 21…. Focus only on the score. If another thought comes to mind, you have to start over.

I have a hard time getting past 15 without thinking about something else, but the first time I tried it I only got to 22. I got better with practice, and it helps.

Louise L. Hay lectures about metaphysics, teaches, and is a best-selling author. She believes that anger, resentment, and guilt do the most damage to our health and that all healing begins with self-love. Here’s a paraphrase of her visualization exercise:

I love the visualization of standing at the seashore looking out at the vast ocean and knowing that this ocean is the abundance of all good things available to us. Look down at your hands and see what sort of container you’re holding. Is it a teaspoon, a thimble with a hole in it, a paper cup, a glass, a tumbler, a pitcher, a bucket, or a washtub? Perhaps you have a pipeline connected to this ocean of abundance. Know that there’s plenty for everyone and that you can’t drain the ocean dry. Your container is your consciousness, and it can always be exchanged for a larger one.

I hold a giant oyster filled with pearls. These are all the gems I have in my possession, with many more that await my discovery. Next to my giant oyster are a red bucket and a shovel so I can find more treasures in the sea.

For centuries, people have believed that the mind has the capacity to heal. The Navajos used imagery to encourage sick people to “see” themselves as healthy. The ancient Egyptians and Greeks believed that visualization released spirits in the brain, which stimulated the heart and other parts of the body.

I’m not suggesting that everyone is able to think or pray illness away, but there’s strong evidence suggesting that people have more control over their well being than the medical community or our culture currently accepts.

Visualization is a mini-massage for the mind that helps me quiet my thoughts so I can breathe through the really tough days.

Chronically Yours,

Lori Hartwell
President & Founder of the Renal Support Network
Changes for Quality
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Diagnosed with kidney disease in 2004, Kathe LeBeau began home hemodialysis in April of 2007, and is presently on the kidney transplant waiting list. She is the Project Manager for Renal Support Network’s weKAN group, and is also a PEPP speaker and HOPEline operator. Kathe lives in the Capital Region of New York State with her husband of 11 years, Loren Fadding.

The regulations needed more emphasis on the patient’s total experience with dialysis. The changes were undertaken as a collaborative effort with input from the renal community, including patient organizations, and reflect improvements in service delivery, the use of more advanced technology and equipment, and, most important, the inclusion of measures considered indicators of the quality of care provided to dialysis patients.

According to nephrologist Barry M. Straube, MD, Chief Medical Officer and Director of the Office of Clinical Standards and Quality at CMS, “This rule was designed with patient care in mind. We’ve added requirements for facilities to conduct a comprehensive assessment of the patient’s health condition when starting dialysis treatment, as well as to work with an interdisciplinary team to develop an individualized care plan for every patient. Facilities must work with patients to achieve and maintain the best possible outcomes of care.”

Some of the key changes are as follows:

- Updating facility requirements to strengthen infection control procedures
- Requiring defibrillators in every dialysis facility to respond rapidly to a heart attack
- Adopting standard water quality guidelines for both in-center and home dialysis use
- Incorporating sections of the 2000 Life Safety Code, upgrading fire safety standards
- Requiring a comprehensive and personalized patient plan of care based on current medical practices and the patient’s unique needs
- Protecting patient rights, including a requirement to inform patients of the right to have an advance directive; a process that explains how a facility must respond to a patient’s grievance; and a policy that requires a 30-day written notice before a facility can involuntarily discharge a patient unless there is a more urgent safety threat
- Instituting a system to help facilities plan programs for improving the quality of patient care
- Prescribing minimum qualifications, training, and national certification for patient care technicians

Questions about the new Conditions for Coverage can be e-mailed directly to CMS at ESRD_Final_Rule_Rollout@cms.hhs.gov, and they will be answered on a rolling basis. In the best interest of your own care and that of your fellow patients, get involved by being informed and educated as the new Conditions for Coverage are implemented.

Other changes are ahead as Congress considers the bundling of dialysis services for payment under the Medicare ESRD program. Many questions and concerns remain to be discussed since patients’ access to care and quality of care must be preserved. Follow the advocacy updates at RSNhope.org and join our patient activist group, the Wellness & Education Kidney Advocacy Network (weKAN). Become active now!

Hear what concerned patients have to say about bundling.
To watch the video “Bundling of Dialysis Services” go to RSNhope.org and click on Advocacy
Healthy Eating with Chef O

Would you like to try some Pineapple Cream Cake? Maybe some Chicken with White Wine Grape Sauce? How about some Black-Eyed Pea Salad? It’s all possible with the recipes created by Oliver Eugene Hale, a.k.a. “Chef O!”

Chef O loves to cook! His desire to cook began around the age of five. He asked his mother if he could help her and he’s been cooking ever since. He takes pride in creating healthy recipes for his customers, including those with kidney disease.

What makes his recipes so intriguing is that Chef O isn’t just a chef… he’s a kidney patient too! For almost 25 years, he’s been dealing with kidney disease caused by untreated high blood pressure. But he didn’t succumb to his illness. Instead, he took action and began a regimen of healthy living that included changes in both diet and exercise.

By eliminating salt and learning how to use other natural seasonings, Chef O was able to improve his health without sacrificing flavor. He also began to exercise. His athleticism even earned him a spot playing tennis in the National Kidney Foundation’s Transplant Games.

He was fortunate enough to receive a kidney transplant on January 29, 1985. It lasted for 22 years, during which he continued to maintain his healthy lifestyle. In December 2007, the transplant failed and he needed to return to hemodialysis. But that didn’t matter to Chef O—whether he was living on dialysis or with a transplant, he continued to cook.

Chef O’s mission is to “enhance a healthy lifestyle of eating for everyone and to teach the utilization of natural or organic foods to improve health and reduce health risks.” He propels this mission in the renal community by performing cooking demonstrations throughout the U.S. for dialysis patients. Chef O has also given demonstrations for health insurance companies, health organizations, and the National Kidney Foundation.

Chef O’s healthy recipes cover the gamut of food tastes: French cuisine, Italian, seafood. You name it, he’s got it! He even has a local television show titled “Chef O’s Place” that airs in the Grand Rapids, MI, area.

Is your mouth watering at the prospect of varying your renal diet? Good, because Chef O has a cookbook coming out later this year. If you want to spice up your life and stay within your dietary restrictions, keep your eye out for this chef who’s on the move!

For more information, visit Chef O’s website at www.ChefO.us.

NOTE: Some recipes in the cookbook may not be renal-friendly. Check recipes with your dietician first.

### Black-Eyed Pea Salad

<table>
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<th>6 servings</th>
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<tr>
<td>1 1/2 cups canned black-eyed peas, drained</td>
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<tr>
<td>1/2 cup chopped celery</td>
</tr>
<tr>
<td>3/4 cup chopped green bell pepper</td>
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<tr>
<td>1/2 cup chopped red onion</td>
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<td>1/4 cup chopped onion</td>
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In a large bowl, combine all ingredients and toss. Refrigerate overnight for better flavors.

### Nutrition Information per serving

(in parentheses if using Splenda substitute)

- Calories: 177 (150)
- Protein: 3.5 g
- Potassium: 216 mg
- Fat: 9.5 g
- Carbohydrates: 21 g (14 g)
- Sodium: 194 mg
- Phosphorus: 69 mg

Recipe used with permission by Oliver Eugene Hale © 2008 by Renal Support Network.
Sara Colman, RD, CSR, CDE, is a nutrition educator and renal dietitian. While helping Dorothy Gordon cook for her husband on dialysis, Sara, along with Dorothy, developed the recipes in *Cooking for David*. Sara also created the “Food Pyramid for Healthy Eating with Kidney Disease.”

**Renal-friendly cookbooks:**

- *Cooking for David: A Culinary Dialysis Cookbook*, by Sara Colman, RD, CSR, CDE, and Dorothy Gordon, BS, RN
- *Living Well on Dialysis Cookbook and Southwest Cookbook for People on Dialysis*, published by Amgen
- *The Renal Gourmet*, by Mardelle Peters, a kidney patient
- *The Kidney Helper Cookbook: Renal Friendly Recipes with a Middle-Eastern Flair*, by Bob Lufty, a kidney patient, and his wife Nathalie, with Mary Pinto, RD

For more information on ordering these and other cookbooks, go to KidneyTimes.com and read *Resources for Living a Healthier Life With Kidney Disease* (Easy Link Access #290). This article also contains links to websites for renal-friendly recipes, tips for renal diets, and tools to calculate nutrition information.
"JUST DO IT!"

Exercise Wisdom from Kidney Peers

“I’ve always loved the challenge of exercise, even before my kidneys failed. Now, the knowledge that I can still DO IT is worth all the work. The best part is... I feel wonderful.” - Jim

“I just feel grateful for my transplant because it gave me the energy to play tennis—something I love to do.” - Dave

Courage doesn’t always roar. Sometimes courage is the little voice at the end of the day that says I’ll try again tomorrow.

– Mary Anne Radmacher, writer, artist
“Exercise keeps me in shape and gives me strength to quickly overcome various health problems. It energizes me to live and enjoy each day to the fullest.” - Stephanie

“After my transplant my doctors encouraged me to tone up the muscles to keep my new kidney in place. I still hate to exercise, but the bonus is I’ve lost weight and I feel fantastic!” - Valerie

“I don’t always like to exercise. But I do it so I have the energy to do the things I like to do. Plus, it makes me feel more alive... and lively! The home dialysis delivery guy didn’t believe me when I said I was the patient because I was out shoveling our long driveway!” - Shari

“I love jogging, since I can hook up to my MP3 player and it’s just me, my surroundings, and my music. It’s how I escape and maintain a balanced life while staying healthy.” - Mandy

“It’s helpful to find a favorite way to exercise so you’ll continue to do it. My current favorites are step and free weights classes and ‘Volkswalking’ (an international walking club).” - Nancy

“Even though I’m on dialysis, I like to exercise because it helps me get done the things I want to get done. Swimming is something I enjoy simply because it’s cooler in the summer months; otherwise, I walk in the park across the street.” - Shawn

**Featured on KidneyTalk:**

Hear how Shari learned to “Overcome the Exercise Excuses!”

Aired July 31, 2007 on KidneyTalk - Listen at RSNhope.org
Announcing: The 2008 Annual KidneyTimes Essay Contest
Theme: “Funding a Dream: Giving Back”

Imagine that you go to your mailbox one morning and inside you find a check in the amount of $100,000! How would you spend it to benefit the kidney community? Tell us, in 750 words or less, what you would choose to do to inspire or help fellow kidney patients. Your essay could win you a cash prize of $500, $300, or $100! Visit KidneyTimes.com for complete guidelines.

You must be diagnosed with kidney disease to enter. Entries must be received by August 31, 2008. Include your complete name, address, phone number, and e-mail address and mail to KidneyTimes Essay Contest, Renal Support Network, 1311 N. Maryland Ave., Glendale, CA 91207, fax to 818-244-9540, or e-mail to essay@rsnhope.org. All essays will be judged on appropriateness to the theme, originality of idea, creativity, and technical expertise.

RSN Programs & Services

weKAN: Wellness & Education Kidney Advocacy Network
A national group of people with kidney disease who advocate on behalf of fellow patients. Live & Give—weKAN’s quarterly newsletter for patients—informs, inspires, and educates patients, family members, and healthcare professionals.

PEPP: Patients Educating Patients & Professionals
PEPP patient-speakers are trained to give educational presentations about kidney-related issues to patients and professionals. To learn about the presentations offered or to schedule a PEPP speaker for a meeting of patients or professionals, go to RSNhope.org and click on Programs, then PEPP.

KidneyTalk!™
Streaming Health, Happiness & Hope over the Internet

KidneyTalk!
Online radio talk show hosted by Lori Hartwell & Stephen Furst, covering a wide variety of kidney-related topics. Listen at RSNhope.org or download podcasts from iTunes.

RSN Renal Teen Prom
Annual prom held both in Southern California and the Washington, DC, area for young kidney patients. Open to teens ages 14 to 24 from throughout the United States.

HOPEline
A toll-free call-in line offering patient-to-patient encouragement and support from operators who have lived successfully with chronic kidney disease. Call 800-579-1970 Monday - Friday, 10:00 a.m. - 8:00 p.m. (Pacific Time).

Regional Patient Lifestyle Meetings
Based on the theme of “Health, Happiness & Hope,” meetings offer a setting where people with kidney disease and their families can learn about issues related to their illness in a relaxed, friendly atmosphere.

KidneyTimes
An online resource with articles written by kidney patients and professionals on medical, social, nutritional, and lifestyle issues. Home of the annual “KidneyTimes Essay Contest.”

KidneySpace
An online discussion forum to air your questions, thoughts, and opinions on lifestyle issues related to diabetes and kidney disease. Go to KidneySpace.com to join the conversation!

For more information about RSN and RSN’s programs, visit our website: RSNhope.org
Given the current debates and pending legislation on therapies for chronic dialysis, it seems appropriate to revisit history to determine how we arrived at our current hemodialysis prescriptions.

Chronic hemodialysis was first done in 1960; it was initially performed once every five to seven days and lasted for 20 to 24 hours. When physicians realized that this was often not enough to decrease the symptoms of kidney failure, they increased the frequency to twice a week for 10 to 16 hours.

A few years later, the frequency decreased again to 8 hours three times a week to facilitate in-center scheduling. Home dialysis patients also followed this schedule but did treatments overnight to minimize the stress on families. By 1972, the norm was closer to 24 total hours of dialysis a week rather than the current standard of 9 to 12 hours a week. Also, at that time 40 percent of patients were on home hemodialysis (HHD).

The transition from the long thrice-weekly schedule to the current one was the result of several factors that followed the extension of Medicare coverage to dialysis in 1973. By 2005, the United States Renal Data System (USRDS) reported that only 0.6 percent of patients were on HHD.*

Although the dialysis time decreased significantly in the United States, this was not the case in Tassin, France, where patients have received 8 hours of dialysis three times a week for over three decades. Mortality rates are less than 50 percent of those in comparable patients in the United States or elsewhere in France.

Several investigators have studied forms of daily dialysis: either short daily hemodialysis or slow nocturnal hemodialysis, mostly delivered at home. Studies on short daily regimens have demonstrated that patients experience improvements in well-being, appetite, and energy; better blood pressure control; and a reduction in the use of medications. Those on overnight dialysis experienced similar results in addition to better phosphate control, fewer dietary restrictions, and fewer hospitalizations. Patient survival was reported to be 81 percent at five years, far superior to the current rate.

Many patients in the United States are asking for more dialysis. They want to feel better and “get their lives back.” However, when reimbursement for more frequent dialysis and home modalities is requested, the response is always, “What’s the evidence that more dialysis is better?”

Given the history I’ve outlined, I’d like to turn this question around and ask instead, “What’s the evidence that dialysis for three to four hours three times a week is enough?”

What appeared to be a good thing in 1973 when Medicare decided to pay for chronic hemodialysis has now evolved into a form of rationing, despite the fact that a number of studies have demonstrated global cost savings, a decrease in hospitalization rates, and the need for fewer drugs.

All patients deserve to feel better. I’ve had a number of patients on longer home dialysis regimens and they wouldn’t consider going back to the standard in-center prescription. The challenge for the future will be to reform the reimbursement system to allow patients to receive more dialysis. A reasonable compromise for some patients may be to increase the duration for thrice-weekly dialysis treatments to 8 hours overnight, either sleeping in-center or better yet, at home, in order to deliver a higher dose of dialysis.

Peter F. Drucker, an Austrian-born American management consultant, said it well: “The best way to predict the future is to create it.” We should strive to have the best outcomes in the world for our patients on dialysis: good health and a long life. All of us have a responsibility to help improve the future by understanding the options and making our voices heard.

Many patients in the United States are asking for more dialysis.

* For a more complete review of history and outcomes as well as references, see the online version of this article at KidneyTimes.com: “I Want More Dialysis... Please!” (EasyLink Access #292)

Summer Sun Tips

✓ Apply sun-tan lotion liberally
✓ Wear a hat
✓ Use sunglasses
✓ Stay in the shade from 10 a.m. to 4 p.m., even on cloudy or rainy days
✓ Minimize salt intake to avoid excessive thirst
✓ Have fun!

Brenda Kurnik, MD, is a private nephrologist in Marlton, NJ, and recently opened a state-of-the-art dialysis center. She serves as Senior Vice President for Business Development and Government Relations for Diversified Specialty Institutes, Inc. (DSI). She was listed as a “Top Doc” by Philadelphia Magazine in 1994, 1996, 1999, and 2002.
**Exercise for LIFE!**

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There are so many ways to exercise. I enjoy weight lifting, which keeps my muscles healthy and my body fit. The treadmill is a great way to burn calories (from my weakness for cheesecake). Water aerobics has proven to be beneficial for me too: It raises my heart rate, and my annual bone density test has shown that I have little bone disease. I also enjoy my conversations with the ladies in the class—there are advantages to being the only man! My wife Elaine and I alternate between water aerobics, weight lifting, and the treadmill.

Exercising with a “buddy” provides companionship, encouragement, and accountability. I’ve made a lot of friends at the YMCA, where my family has had a membership for many years. My water aerobics class celebrates milestones with monthly lunches, and it was during my regular workouts that I met Joe, my role model. Sometimes I find myself trying to keep up with him, not only in exercising but also in sharing jokes. I’m blessed to have such an extraordinary man in my life. Did I mention that he’s twice my age? As Joe says, “I’m 82 years young. What’s your problem?”

Most YMCAs offer discount programs based on ability to pay. Other fitness centers may also offer discounts to seniors, students, and families. My family membership costs about $400 a year, which is a little more than a dollar a day. Most people spend that much on a drink or snack. Why not invest the money in your health instead? It’s priceless!

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**Dialysis without Fear**

by Daniel Offer, MD; Marjorie Kaiz Offer; and Susan Offer Szafir

Oxford University Press, 227 pages Available at Target, Amazon.com, and other stores

A psychiatrist who has kidney disease, his wife (a researcher), and their daughter (a writer) have written a book called *Dialysis without Fear*, a handbook for people with kidney disease and their families. Daniel and Marjorie Offer and their daughter Susan have experienced years of dialysis as a family and as a team. This project came about because they couldn’t find a book that explained in simple terms the soup to nuts details of life on dialysis. It’s geared for those on dialysis and their families, but would be helpful to everyone who lives with chronic kidney disease.

All issues pertaining to Daniel’s life with kidney failure are chronicled. From what access to choose (an access being the site where blood will enter and exit the body) to a step-by-step account of a typical dialysis treatment—which Daniel humorously calls the “suds factory” (since dialysis cleans the blood)—the authors didn’t miss a single aspect of kidney failure.

This material is extremely beneficial for a new patient. Technical information and medical jargon is presented in language that a layperson can understand. Important matters such as dealing with the psychological impact of kidney failure, understanding whether transplantation is an option, knowing your rights in the workplace, dining out, and traveling are all explored.

The Offers emphasize that support from a spouse, friends, and family is very important. Kidney failure can be a challenging and bumpy road, but the Offers want you to know that it can also be doable. This book empowers readers with the strong message that life goes on and that great things are still possible. Dialysis patients can accomplish almost anything: They can work, get an education, and raise a family; they can even travel the world!

I wish this book had been written when I began my journey of dealing with kidney failure in 1996—it would have been a tremendous source of information and hope.

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Julie Glennon received a successful kidney transplant in 1999 after being diagnosed with both lupus and chronic kidney disease. She keeps active by volunteering with her local chapter of the American Association of Kidney Patients and as a weKAN patient activist and HOPEline operator with the Renal Support Network. Julie is currently renovating a 1920s historic house in Florida with her architect husband.

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Martinlow Spaulding, MAA, is Operations Manager for the Indianapolis Baroque Orchestra and a two-time recipient of ESRD Network 9/10’s Felter Patient Award. Diagnosed with kidney disease in 1992, he’s received two transplants, both from his siblings. He’s a weKAN patient activist and a PEPP speaker with the Renal Support Network. He lives in Indiana with his wife and six children.
“Victoria,” a 32-year-old woman, was having difficulty with leg cramps during her treatments. She began exercising for only five minutes a day on a cycle wheeled up to her chair. Within two weeks, she was exercising for 30 minutes during each treatment and her leg cramps had subsided. Victoria noticed that not only were the cramps gone, but her legs were stronger, she had more energy after her treatments, and the treatments themselves seemed to go by much faster!

Many others at the dialysis clinic have discovered these same benefits from exercise. While Victoria noticed many physical benefits, others have found psychological benefits.

“John” loves to exercise. He also loves chatting with his dialysis neighbors, doing crossword puzzles, and taking walks. Despite his many challenges, he has found that he’s a much happier person with a more positive outlook on life. When did John notice this change? The same time he discovered the Sit-Fit Exercise Program.

Other patients have noted more self-confidence, improved concentration, and better sleep! Can you imagine? All of this from exercise!

These are just some of the benefits you may discover from exercise. But that just scratches the surface. Your doctor will be able to see lower blood pressure, stronger bones, better glucose tolerance, and a decreased risk of cardiovascular disease, among other things.

Now, how do you get involved in an exercise routine? It takes just one step. Tell your doctor that you want to have more energy, fewer cramps, a more positive attitude, and a healthier, more enjoyable life.

NOTE: Names changed to protect identity.
To Your Health

Exercise for LIFE!
by Martinlow Spaulding, weKAN Patient Activist, PEPP Speaker

I find it funny when people say, “You look good! Why do you exercise?” I respond, “Maybe it’s because I exercise that I look good.”

When I encourage people to exercise, they often say, “I don’t have time in my busy life.” I then ask, “How is your life so busy?” The usual answer is, “I work nine hours a day with an hour commute.” That’s when I share that I’m a daddy of six active children, an arts administrator, and a religion teacher at church. And oh, by the way, I also have kidney disease. But I’ve made a commitment to myself to exercise at least three times a week. Life is about choices, and I choose to “Exercise for LIFE!”

For me, learning about the benefits of exercise was my “ah-ha” moment. The possible benefits of regular exercise (especially for those who are living with kidney disease) include lower blood pressure, more energy, greater endurance and flexibility, less stress, less risk of heart disease, an active sex life, a better self-image, and a positive outlook.

Everyone has a different capacity for exercise and should therefore discuss any proposed exercise program with a doctor. A person should stop exercising immediately if any of the following occur: shortness of breath, chest pain, severe headache, or a racing heart rate.

Thanks to our sponsors!

To Your Health

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