PSNhope.org

Volume 8, Issue 1 • Spring/Summer 2012 The bi-annual update helping to educate and motivate people living with chronic kidney disease.

Headline News

Anemia Management: Understanding the New Guidelines

by Klemens Meyer, MD, and Douglas Johnson, JD, MD

CLOSED

Closed?!! But I'm still hungry after trying to get

blood from those anemic people on dialysis!

Over the past few years, you've probably heard arguments about the hemoglobin level that's best for

people with kidney disease. In this article. we'll provide background on anemia and the drugs used to treat it: these are called erythropoiesis (er-ith-ro-po-eesis) stimulating agents (ESAs).

Before ESAs, about one-third

of patients on dialysis had hemoglobin levels below 9 grams/deciliter. Many people whose levels are that low feel

tired. (Normal levels are between 12 and 16 for women and between 14 and 18 for men.)

> The risk of receiving at least one blood transfusion a year when your hemoglobin is below 9 is about 1 in 3. Transfusions make it harder to find a matching kidney transplant. Because of the risk of lifethreatening complications, doctors often recommend

> > a transfusion when hemoglobin values drop below 8.

For almost 20 years, most people thought that having

a higher hemoglobin level was good for patients with kidney disease, that ESA treatment would make people

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Look Inside!

- LORI'S LINES I'm Taller Than I Look
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- PERSPECTIVES Aging in Dog Years

Contact RSN to get Live & Give delivered to your mailbox (see page 3).

Please inform us if your address has changed. Thank you!

ANNOUNCING

The 10th Annual KidneyTimes Essay Contest

Dust off that old typewriter or power up your iPad. You could win \$500!

Details on page 11

Professional Points

Dialyze to Live, Don't Live to Dialyze by Lauren D. Vazquez, PhD

Coping with a chronic illness like end-stage renal disease is stressful. Dialysis schedules, fluid restrictions, and multiple medications are only a few of the stressors you deal with every day.

You might start to feel that instead of "dialyzing to live," you're just "living to dialyze," and wonder whether being entirely consumed by what you have to do is worth it.

This can happen all too easily when

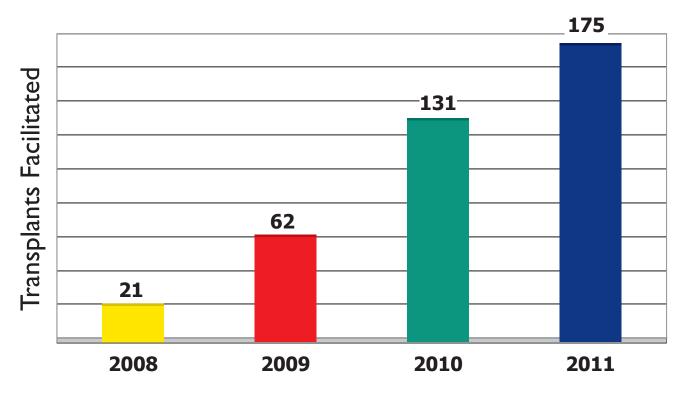
your life becomes centered solely on your physical health.

Most people expect to have a stressful day once in a while. But if you're coping with a chronic illness, one stressful day can easily turn into an endless series of stressful days, and soon you could find yourself no longer enjoying life the way you used to. When this happens, it's important to break the cycle of bad days by helping the good things in

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YOUR BEST CHANCE

If you have an incompatible or poorly compatible donor



The National Kidney Registry has facilitated more transplants than any other exchange program in the world

For a referral to a member center go to www.kidneyregistry.org					
Emory Transplant Center	Atlanta	GA	Christiana Care Health System	Newark	DE
University of Maryland Medical Center	Baltimore	MD	Newark Beth Israel Medical Center	Newark	NJ
Walter Reed National Military Med. Center	Bethesda	MD	Robert Wood Johnson	New Brunswick	NJ
Brigham and Women's Hospital	Boston	MA	Mount Sinai Medical Center	New York	NY
Massachusetts General Hospital	Boston	MA	New-York Presbyterian Columbia	New York	NY
Montefiore Medical Center	Bronx	NY	New York-Presbyterian/Weill Cornell	New York	NY
Fletcher Allen Health Care	Burlington	VT	St. Luke's Transplant Center	New York	NY
Medical University of S Carolina	Charleston	SC	Sentara Norfolk General Hospital	Norfolk	VA
Rush University Medical Center	Chicago	IL	St. Joseph Hospital CA	Orange	CA
University of Chicago Medical Center	Chicago	IL	Lucile Packard at Stanford	Palo Alto	CA
University of Illinois MC	Chicago	IL	Stanford University Medical Center	Palo Alto	CA
Cleveland Clinic	Cleveland	OH	Thomas Jefferson University Hospital	Philadelphia	PA
Ohio State University Medical Center	Columbus	OH	University of Pennsylvania Hospital	Philadelphia	PA
Hackensack University Medical Center	Hackensack	NJ	Allegheny General Hospital	Pittsburgh	PA
Our Lady of Lourdes	Haddon Heights	NJ	Starzl Transplantation Institute/U Pittsburg	Pittsburgh	PA
Pinnacle Health Systems	Harrisburg	PA	Virginia Transplant Center	Richmond	VA
Methodist Hospital, Houston	Houston	TX	Riverside Community Hospital	Riverside	CA
Indiana University Health Transplant	Indianapolis	IN	UC Davis Medical Center	Sacramento	CA
Saint Barnabas Medical Center	Livingston	NJ	Barnes-Jewish Hospital	St. Louis	MO
Loma Linda Medical Center	Loma Linda	CA	University of Utah Medical Center	Salt Lake City	UT
Keck Medical Center of USC	Los Angeles	CA	Sharp Memorial Hospital	San Diego	CA
St. Vincent Medical Center CA	Los Angeles	CA	California Pacific Medical Center	San Francisco	CA
UCLA Medical Center	Los Angeles	CA	UCSF Medical Center	San Francisco	CA
University of Wisconsin, Madison	Madison	WI	Seattle Children's Hospital	Seattle	WA
Loyola University Medical Center	Maywood	IL	University of Washington Medical Center	Seattle	WA
Methodist University Hospital Tenn	Memphis	TN	Tampa General Hospital	Tampa	FL
Intermountain Medical Center	Murray	UT	Lankenau Hospital	Wynnewood	PA
	-		•	-	

I'm Taller Than I Look!

by Lori Hartwell



I've always been petite. Right now, I stand a whopping 4'10". Growing up, I was always the shortest one in my class. One

year, I stood on my tippy toes during our class photo so I could be moved to the second row, but I got a cramp right as the shutter clicked. Needless to say, I'm not in the picture.

Looking so young was frustrating to me because my mind was always older than I looked, and I wanted to scream when people treated me like a child! I also wear a size 2 children's

The Renal Support Network is a patientrun nonprofit organization whose mission is to identify and meet the nonmedical needs of those affected by chronic kidney disease.

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Thank You

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shoe, and finding shoes that have a heel can be a challenge. Finding a shoe that didn't light up when I walked or have a Smurf logo on the side was difficult too. When I found a store called Cinderella Shoes, I thought I'd died and gone to heaven. Racks and racks of heels in my size! I was so thrilled that I thought my prince would pop out of one of the doors in the store! The one problem is that the height of the heel has to be proportional to the length of your foot. So, the shorter the foot, the shorter the heel should

be if you want to walk with any grace at all. At first, I got heels that were too high, and people were beginning to think I was drunk! That wasn't the image I wanted to convey; I had no desire to be Snooky from "The Jersey Shore."

By my early twenties, it was apparent that I wasn't going to get any taller. My mom is only 5 feet tall, so kidney failure at a young age coupled with her genes meant that I really didn't have a chance. I decided that it was time to work with what I had.

Here are a few tips to help you look taller: manage your weight, stand up straight, get the right hairstyle, see that your clothes are coordinated, and, of course, wear a heel that's comfortable to walk in.

Remember, too, that being petite can work for you as well as against you. When I was 21, I went skiing and the guy at the counter handed me a child's lift ticket, so I saved a few bucks. However, it's not so helpful when you're on a date and

they hand you the children's menu.

In my late twenties, I learned that being petite helped me stand out in business. Often, people had low expectations because I was short and female, so it was easy to surprise them. I could fly under the radar, and they never saw me coming! I remember one meeting with a top executive. He was laying out what he thought I should be doing. I just replied, "This is the way I see it," and went on to share my vision. He realized that he'd

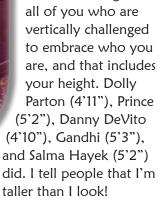
underestimated me. and

I gained his respect by standing up for myself.

> Studies have shown that shorter people are less likely to break a bone when they fall. I guess it's because we don't have very far to go.

> So I encourage all of you who are vertically challenged to embrace who you your height. Dolly Parton (4'11"), Prince

> > 3



Although you might be small in stature, you can still be large in your achievements, your friendships, and your goodwill. 🖂

Lori with Mark Eaton,

NBA All Star. Mark is 7'4".

Lori Hartwell, Founder & President of the Renal Support Network (RSN), was diagnosed with kidney disease at the age of two. In 1993 she founded RSN to instill "health, happiness, and hope" into the lives of those affected by chronic kidney disease. Lori is also the author of the book "Chronically Happy: Joyful Living in Spite of Chronic Illness" and is a four-time kidney transplant recipient.



Tips for Looking Good Despite Kidney Disease

Whether we're watching TV or looking at magazine covers in the grocery store, we're bombarded with images of beautiful people. Beauty is a billion-dollar industry. Despite the new anti-aging products that seem to pop up every week, the fact is that none of us is getting any younger. Now add chronic kidney disease (CKD) to the equation. Of course, we non-Hollywood types could never compete with models who are airbrushed by famous photographers, but here are some tricks and tips that help me look healthier.

Let's start out with our skin. Medication and the dialysis procedure itself both affect the skin. During dialysis, our skin shrinks as fluid is removed, and on nondialysis days, our skin stretches because we're retaining fluid. This makes our skin very dry, so it's important to be diligent about using body lotion. In the daytime, make sure that lotion has a high sun protection factor to guard against skin cancer. Those who have had a transplant are especially at risk because the immunosuppressant medications make them more sensitive to the sun. Having your dermatologist do a complete skin check twice a year is essential.

Taking large doses of prednisone for so many years made my skin—especially the skin on my shins—very, very thin. In addition, I have a lot of bruises on my

legs that have never gone away. My dermatologist told me that these marks are in fact not bruises but rather stains from iron treatments. Unfortunately, he confirmed that these

stains will decorate my legs forever. Laser treatments only made them worse. I've tried unsuccessfully to cover them with makeup, and nothing works for me. If you haven't taken prednisone for as many years as I have, your skin will be in better condition and foundation should work. I also have heard that stage makeup works for some people.

Within 24 hours of starting to take those large doses of prednisone to treat my lupus, I had a rash on my forehead called steroid acne. That certainly did a number on my self-confidence. I tried everything to get rid of it, but nothing worked. Later, as the prednisone dose was decreased, the acne did improve, only to return 10 years later (in 1999) when I received a transplant and the dose was increased.

One evening I was watching an infomercial and decided to order the product, a skin care system called Proactiv®. Within three weeks, the acne was gone. Now 12 years later, I still get acne sometimes but it clears up quickly with Neutrogena® Rapid Clear (Acne Eliminating Spot Gel), which can be found at many stores.

We know that being anemic or just plain sick can make us look pale. Also, those taking immunosuppressants must stay out of the sun, and others just don't have the strength or the motivation to go outside all that often.

Tanning cream keeps me from looking like Casper the Friendly Ghost. I've tried every tanning cream on the market, and they've come a long way in the past decade. I recommend using a moisturizer with a tanning cream in it about twice a week. This

> is easier to use than a general tanning cream because the margin of error of turning a weird orange color is very small. Another tip for looking a bit healthier is to apply a

little blush to your cheeks. Bronzer is somewhat like blush, but it's a bit more on the tan side. I use it occasionally in addition to blush for a sun-kissed look.

When you're up all night because of pain, restless leg syndrome, or insomnia, your eyes look tired the next morning. Under-eye concealer is quite



Julie Glennon received a successful kidney transplant in 1999 after being diagnosed with both lupus and chronic kidney disease in 1998. She keeps active by

volunteering with The Kidney Association of South Florida where she lives with her husband. She is also a weKAN activist and KidneySpace moderator with RSN.

helpful in covering those dark circles. Concealer is like foundation but a bit more concentrated.

Medication, infection, CKD in general, autoimmune diseases, and high fevers can cause our hair to thin. I know that many women (and their husbands) like long hair, but after losing all my hair on three separate occasions, I find that shorter hair works best for me.

The first time I lost my hair was in 1993, when I was being treated with Cytoxan® for lupus. I ended up wearing a wig, which was nice on my wallet—no more haircuts, no more dye jobs! My hair eventually grew back, but it fell out twice more over the next few years. During times when I don't feel good my hair tends to get thin, so keeping it shorter makes it look thicker and makes me feel more comfortable with my appearance.

We've all experienced swelling in our legs, feet, and ankles, but I never knew that all soft tissue can swell. When my kidneys were failing, I would wake up in the morning and not recognize myself in the mirror. My face, and especially my eyelids, were retaining a lot of fluid. I found it embarrassing, so I kept using more pillows when I slept. Eventually I used three, I think, so I was basically sleeping sitting up. It helped, but the fluid was only building up in my abdomen instead. I knew that it was nothing but vanity, but I'd rather wear pants with an elastic waist than have my face look so distorted.

I'm sure that other women have great tips for looking good, but these help me look a bit healthier and feel more self-confident. 🖾

Share your tips on KidneySpace.com under Lifestyles, then "For Ladies Only"

Anemia Management

Continued from page 1

both feel better and live longer. It seemed that the only reason to limit doses was cost.

First, guidelines said that the hemoglobin level should be kept above 10, later that it should be kept above 11. But in 2006 and 2009, three studies showed that using ESAs

Hemoglobin

carries oxygen in the blood and is contained in red blood cells.

Hematocrit

represents another way of measuring how much oxygen the blood can carry.

Anemia

When you have a low hemoglobin or hematocrit level in your blood.

to raise hemoglobin values above 13 didn't make people live longer than keeping them above 9. In fact, high levels seemed to be associated with a risk for stroke. It's important to note that this risk was found with high doses of ESAs; people who required small doses to achieve high hemoglobin levels did well.

Dialysis Clinic, Inc. (DCI) data show decreased mortality and hospitalization for patients who have a high hemoglobin level but receive small doses of ESAs. One current theory holds that it's not the high hemoglobin level that's harmful, but rather the large ESA dose needed to achieve it.

If using ESAs to raise the hemoglobin level above 13 doesn't make patients with kidney disease live longer, does it make them live better? Does a hemoglobin level of 8, 10, or 12 make a difference in how

Douglas S. Johnson, JD, MD, is Vice Chairman of the Board of Dialysis Clinic, Inc.

Klemens B. Meyer, MD, is Professor of Medicine at Tufts University School of Medicine, Director of Dialysis Services at Tufts Medical Center, and Medical Director for Information Technology at Dialysis Clinic, Inc. people feel and in what they can do?

In 2011, after looking at all available studies, the Food and Drug Administration (FDA) determined that there wasn't enough evidence to conclude that raising

hemoglobin levels above 10 improved quality of life and that therefore ESAs shouldn't be given for that reason. According to the FDA, the only reason to give ESAs is to avoid transfusion.

Because of the risk of stroke in the studies targeting hemoglobin values above 13, the FDA recommends that ESAs be stopped or the dose reduced as the hemoglobin level approaches 11. The FDA rescinded a previous recommendation that ESAs be used to keep the level between 10 and 12.

Medicare is bound by FDA decisions and will therefore stop considering that a hemoglobin level below 10 indicates poor care, but will continue to consider that values above 12 indicate poor care. Medicare will reduce payments to dialysis facilities if the average hemoglobin values of too many patients exceed 12, but won't penalize facilities for low values.

As a consequence of the labeling change, some nephrologists are hesitant to prescribe even a small ESA

ESAs

(erythropoiesis stimulating agents) include erythropoietin (er-ith-ro-po-e-tin) or epoietin (ee-po-i-tin).

These are both referred to as EPO, and sold as Epogen® and Procrit®.

Another ESA is darbepoietin (dar-be-po-i-tin), sold as Aranesp®.

dose when a patient's hemoglobin exceeds 11—they're afraid of being sued if someone has a stroke.

A second change has also influenced dialysis ESA dosing. Until 2011, Medicare paid for ESAs outside the bundled dialysis payment; however, the 2011 expanded bundle includes ESAs. Until 2011, there was an



incentive for dialysis providers to give larger doses of ESAs, whereas now there's an incentive to give smaller doses.

Although the FDA has concluded that the evidence doesn't support a

relationship between hemoglobin and quality of life for the average person, not everyone is average. Individual patients have convincingly described how their vigor, ability to function, and sense of well-being improve when their hemoglobin level exceeds 10 or 11—or even 12. As a patient, then, what should you think?

Neither of us has kidney disease, and we offer our advice knowing that we haven't walked in your shoes. We think that we'd want to receive the lowest ESA dose needed to give us the energy we want. We'd observe our own vigor and functioning and relate these to our hemoglobin level. If having a level of 11 or 12 made a big difference in how we felt and could be achieved with modest doses of ESAs, we wouldn't be frightened off by a slight increase in the risk of stroke. However, if it didn't make a big difference, we'd settle for a lower hemoglobin level. We'd want our level to be monitored frequently

and to have doses adjusted systematically.

At DCI, ESA doses for 90% of our patients are adjusted by computerized protocols, with a target hemoglobin of between 10 and 12. Patients and doctors can deviate from these protocols. We've found that if we stop ESAs when the hemoglobin level exceeds 12, 90% of our patients have values between 10 and 12

for at least 6 months of the year.

We hope that this summary is helpful. You'll receive the best possible care if you participate with your nephrologist and dialysis clinic in determining the anemia therapy that's best for you. You're the only one who knows your own goals for your care.

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HOPEline

If you have chronic kidney disease and don't know what to expect...

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English Monday – Friday 10 AM – 8 PM (PDT)

Support from someone who's been there.



Si tiene enfermedad renal crónica y no sabe que le espera...

Llame (800) 780-4238

Español Lunes – Viernes 10 AM – 8 PM (hora del Pacífico)

Alguien que ya estuvo ahí le ofrece apoyo.

A program of the Renal Support Network. For more information visit RSNhope.org

Dialyze to Live

Continued from page 1

your life become enjoyable again. What I'm advising is improving your quality of life. It's easy to become preoccupied with quantity of life—a measurable lifespan—but quality of life refers to the personal satisfaction you derive from that life.

Many people with chronic health issues find themselves frustrated because they're just not living the way they want to. Part of the stress of coping with end-stage renal disease and dialysis involves the many behavioral and lifestyle changes that you're required to make. Finding effective ways to deal with that stress is essential to taking control of your life and living the way you want to.

The following strategies emphasize promoting a better quality of life while coping with end-stage renal disease.

Schedule Pleasurable Events

Part of taking control of your emotional well-being involves intentionally scheduling, committing to, and following through with rewarding activities. Once you do, you might begin to notice that you feel better. Think of some activities that could help the good things in your life feel enjoyable again. What are some strategies you could use to make sure you follow through and

participate in the activities you've scheduled even if you don't particularly feel like it?

Maintain Physical Activity

Regular physical activity can improve your health and quality of life in a number of ways. Exercise is not only a good way to minimize stress and increase energy, it also helps regulate biological rhythms and mood and control weight. Think of some physical activities you might enjoy and some of the personal benefits you could gain from them.

"Quality of life" refers to the personal satisfaction you derive from your life.

Take Time to Relax

Relaxation is the act of letting go of any stress and worry you might be experiencing. Learning effective ways to relax can make you feel calmer and more serene. One way is by controlling your breathing. Focusing your attention on taking slow, deep breaths allows your mind and body to relax. You can use deep breathing in a variety of settings—during dialysis, in bed at night, or in the car. Think of some situations in your daily life where deep breathing might be helpful.

Decide What's Most Important

People with chronic health issues have to look at life a little differently from other people. Studies suggest that those who manage to adjust actually report feeling more resilient than they did before. As Albert Einstein once said, "In the middle of difficulty lies opportunity."

Deciding what's truly important to you—family, spirituality, or anything you find intrinsically rewarding—and then embracing it are vital steps toward helping you successfully navigate the stress of coping with a chronic illness and improving your quality of life.

Remember, too, that coping with end-stage renal disease is a process. Using these skills should facilitate the process of adjustment and thereby improve your quality of life. Being satisfied with your quality of life is the difference between "dialyzing to live" and "living to dialyze."

Dr. Lauren Vazquez is a clinical health psychologist at Ochsner Medical Center in New Orleans, Louisiana. She earned her PhD in clinical psychology from the University



of Florida. Dr. Vazquez has been involved in a variety of research and has authored over 30 research manuscripts, abstracts, and book chapters spanning health psychology topics.



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Keep a Spring in Your Step

by Jason Luk, PT, DPT

Have you noticed pain or stiffness in your legs? Is a short walk to the bathroom starting to feel like a chore? Maybe you're beginning to trip over your own feet or walk with a slight limp. Swelling of the ankles could be the culprit.

People with kidney disease, especially people on dialysis, are prone to develop swelling of the ankles due to fluid retention. Swelling not only causes joint stiffness, but it can often lead to pain as well. And when your ankles are swollen, the mobility of those joints can be compromised, which in turn can impair your ability to walk.

One of my patients came in and complained that her left hip was hurting. I soon discovered that her right ankle was very stiff and didn't have full mobility. As a result, she was compensating by putting more pressure on her left hip as she walked. Her gait was abnormal, with her left hip rotating up slightly and causing pain in the other hip. Whenever your gait is abnormal, it will usually lead to pain somewhere in the body.

I've been working with her on a series of stretches and exercises (some of which I will explain later), and I encourage her to always wear shoes with good support.

What to Look For

The easiest way to tell whether your ankle is swollen is to compare one against the other. When swelling in both ankles is suspected, a simple test can indicate how severe the problem is. Apply moderate pressure with your thumb to the swollen area. If an indentation is left behind, a form of swelling called pitting edema is present. And if the indentation doesn't go away after 30 seconds, the amount of swelling is significant.



Got questions?
Need someone to talk to?
Want to learn what others have discovered?
Join the conversation at KidneySpace.com!

KidneySpace.com is an online discussion forum where you can discuss your questions, thoughts, and opinions on lifestyle issues related to transplant and kidney disease.

KidneySpace.com is a program of the Renal Support Network.

Other signs to look for include not fitting into your shoes any longer and losing the ability to flex your ankle to a normal range. Also, you may notice that your ankles are swollen before dialysis or after you've been standing or walking for a while. The fluid around the joint makes it hard



to improve the mobility of your ankle when swelling is present, so exercises and stretches should be performed when the swelling is down.

Limiting the Swelling

Fortunately, there are several things you can do to help limit swelling. The most direct method involves controlling your salt intake, adhering to your daily fluid allowance, taking diuretics, and keeping your feet up. But one of the most effective ways to address swelling and stiffness simultaneously is to exercise and stay active.

The simple exercises illustrated on the following page, when performed safely and consistently, can limit swelling and improve your mobility at the same time.

To gain the greatest benefit, make these exercises a consistent part of your daily routine. Other simple adjustments, such as minimizing prolonged sitting and getting up frequently, will help you maintain mobility.

When to Seek Medical Treatment

If your swelling and decreased mobility don't respond to diet, dialysis, medication, and exercise, it's time to talk to your doctor. Not dealing with these problems can lead to significant functional impairment and the loss of your ability to walk. Additional symptoms such as chest pain and difficulty breathing can be signs of a more serious condition, so don't ignore your symptoms or hope that they'll go away.

Dr. Jason Luk, PT, DPT is a physical therapist. He and his wife own a clinic which specializes in treating patients with orthopedic injuries, and stresses a whole-body approach to treatment. Joseph S. Luk Physical Therapy, Inc. is located in Glendale, CA.

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Renal Support Network (RSN) is a nonprofit, patient-focused, patient-run organization that provides non-medical services to those affected by chronic kidney disease (CKD). Through a variety of programs RSN strives to help patients develop their personal coping skills, special talents, and employability by educating and empowering them (and their family members) to take control of the course and management of the disease.



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For more information about RSN's programs, visit our website:

Calf Raises



When you're either sitting or standing, push your heels up from the floor and shift weight onto your toes. In addition to strengthening an important muscle for walking, this exercise activates a pump in our calf muscles that helps move fluid back toward the heart.

Leg Extensions



As you sit, slowly alternate straightening out your legs. This exercise again activates a pump to help drain fluid, but it also helps strengthen your thighs and stretch the muscles at the back of your legs.

Calf Stretches



Face the wall and brace your hands against the wall, then lunge forward. Make sure that your back leg stays straight and that the heel stays on the floor. Holding this position for 30 seconds helps stretch the muscle that inhibits ankle mobility the most.

Ankle Alphabet



Elevate your foot slightly above the floor, and use it to draw all of the letters of the alphabet, leading with your big toe. Try to make the letters as big as possible because this will promote the full range of motion for your ankle.

Texas Hold'em Celebrity Charity Poker Tournament

Held in Los Angeles to benefit the Renal Support Network

Coming October 6, 2012... stay tuned for more information at RSNhope.org

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Aging in Dog Years? Continued from page 12

Spiritual

It's important to fill your life with activities that awaken your spirit and stir your soul. Some examples are meditation, massage therapy, religion, and the arts; or finding joy in nature, listening to music, and (one of my favorites) submerging in warm water.

Mental

Admittedly, this is a tough one. The constant management of an illness can wear you down. When it gets the better of me, I know that it's time to seek support by talking with a life coach, a counselor, or a friend; also, I focus on finding meaning and purpose

in life. Sometimes I light candles, fill the bathtub, climb in, and have a good cry. Once the candles have burned down, I know that it's time to move on.

Exercise can be a

Physical

struggle, not because
we lack motivation,
but because of
physical constraints.
Unfortunately, many of
us have had kidney disease for
years, and time, medication, and
surgeries have taken their toll on
our bodies. Joint problems, heart
problems, or diabetes or other
comorbidities make exercise more
challenging. I determined that the
way for me to keep moving was
through physical and occupational
therapy (PT/OT).

PT/OT is extremely helpful in devising an exercise plan, no matter what limitations you may have. Your physician can refer you to a therapist, and most insurance plans and Medicare will pay for a certain number of visits per year. Your regimen might include the following activities, among others:

- Stretching, which helps develop flexibility and balance
- Walking, which is great exercise and a wonderful social outlet (but it can put pressure on your joints)
- Swimming, which is the perfect choice for people with joint issues
- Biking, which provides an excellent low-impact workout
- Yoga, which encompasses different styles that focus on areas such as breathing, flexibility, relaxation, strength, and balance
- Workouts on a treadmill or an elliptical trainer or elliptical step machine, which are good for the cardiovascular system



Elliptical trainers or recumbent step machines provide benefits similar to those derived from running, but without the stress on your joints, especially if you use a recumbent step machine, which allows you to sit while you exercise.

Emotional

Caring for our physical, spiritual, and mental well-being promotes emotional health as well. Additional ways to promote emotional health involve:

- Surrounding yourself with good friends and people who support you
- Pampering yourself

- Cooking a great meal with friends or people you love
- Eating chocolate (an easy one, but take your binders!)
- Being grateful for what you have

Social

Chronic illness can make us feel isolated—utterly alone—even when we're surrounded by family and friends. For most of us, this feeling of loneliness is transient, but if it lingers, there are ways to deal with it:

- Volunteering
- Dancing (even cleaning the house to your favorite music to get you moving and smiling)
- Laughing
- Loving (embrace the miracle of love wherever you find it: in a spouse, a child, or a pet; in friendships or strangers who need a hand or a compassionate glance)

Living with kidney disease makes us keenly aware of what we eat, how much we drink, which pills we need to take, and which specific lifestyle changes our treatment demands. Yet caring for ourselves involves so much more. Taking a holistic approach can help us marvel at the mystery and magic of life and allows us to be all that we can be.

As Teddy Roosevelt put it, "Do what you can, with what you have, where you are." (R

Celeste Castillo Lee currently is a Senior Project Manager in the Office of the Provost at the University of Michigan. She also served as chief of staff to the President and CEO, Duke University Health System, and the Chancellor for Health Affairs at Duke University where she was active in the Patient and Family Centered Care initiatives. Celeste's multiple memberships in non-profit health organizations keep her busy as an advisor and advocate primarily in Michigan and North Carolina as well as internationally. Celeste resides in Ann Arbor, MI, with her husband, Daniel Lee, PhD, and their son, lonathan, 21.

The 10th Annual KidneyTimes Essay Contest

THEME

What small act of kindness by a healthcare professional made a difference in your life?

Kidney disease can be difficult. Yet just one word or kind act from a healthcare professional can make all the difference. These people are our heroes. Tell us, in 750 words or less, how a healthcare professional made a difference in your life. Your essay could win you a cash prize of \$500 (1st prize), \$300 (2nd prize), or \$100 (3rd prize)!

- Entries in Spanish are also accepted and the Spanish essay winner will receive \$100.
- All entries must be postmarked or received by 12:00 PM (Eastern Time) on August 1, 2012.
- You must be diagnosed with kidney disease to enter.
- Limit one entry per person.
- All entries become the sole property of the Renal Support Network and will not be returned.
- Essays will be judged on appropriateness to the theme, originality of idea, creativity, and technical expertise.

Visit RSNhope.org for more information.

Submission Guidelines

Include with your essay a separate page with your complete name, address, phone number, and e-mail address (if applicable).

Submit your essay in one of the following ways:

E-mail to: essay@rsnhope.org
Fax to: 818-244-9540
Mail to:
KidneyTimes Essay Contest
Renal Support Network
1311 N. Maryland Ave.
Glendale, CA 91207

You can make a difference!

The Renal Support Network relies on charitable contributions to provide hope to patients with kidney disease.

We appreciate your help!

To make a tax-deductible online donation go to RSNhope.org

(click on Contribute at the top of the page) Or call 866-903-1728 to donate by phone RSN accepts all major credit cards

Make checks payable to
"Renal Support Network" and mail to:
Renal Support Network
1311 N. Maryland Ave.
Glendale, CA 91207



2012 Renal Teen Prom

Held January 15 at Notre Dame High School Sherman Oaks, CA

Watch the video, see more photos, and read the news coverage at RSNhope.org



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Aging in Dog Years?

by Celeste Lee

As patients with chronic kidney disease/end-stage renal disease, we're constantly setting a new normal as we age. We become experts in simultaneously holding onto hope and achieving acceptance. We do all we can to maintain our physical health with the help of medical intervention and a renal diet.

But we must also continue to think expansively when it comes to maintaining our overall health. Over the past 30 years, I've come to define health as incorporating my entire being: spiritual, mental, physical, emotional, and social.

I was diagnosed with Wegener's granulomatosis, which destroyed my kidneys in 1982, when I was 17. My doctor gave me a copy of "Anatomy of an Illness" by Norman Cousins and said, "Celeste, you're beginning your life-long journey with chronic

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illness, and you have two choices: be a passive observer, allowing others to take the driver's seat, or be the driver, taking control of your life when you can, experiencing the adventure, and setting your limits."

I chose to be the driver. February marks my 20th year on the

transplant list—7,300 days. I'm 47 years old, but look and feel 15 years older. I was on hemodialysis from 1983 to 1986, when I received a cadaveric transplant that lasted until 1995. My kidney began rejecting in 1992, however, so I went back on the list and transitioned onto peritoneal dialysis in 1996 and hemodialysis in 2004.

During these years, I attended college, created a family, and built a

Celeste Lee, happy to be in the driver's seat of her life.



career in higher education administration while at the same time being an advocate. Those years were full of love and joy, pain and sorrow, stress

and growth. I believe that it was necessary for me to experience all of them to help me develop the coping mechanisms I needed for overall good health.

Let me share some specific tools that have helped get me through the past 30 years. These techniques support almost all aspects of health, whether you have a chronic illness or not.

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