

Most people who know me know that I have a lot of medical issues ranging from chronic renal failure to mobility problems resulting from renal disease. Not as many people know that for most of my life, I've also battled mental illness.

I can remember having my first big bout of depression and suicidal thoughts at age seven. As an adult, it's hard to look back at that seven-year-old who felt so hopeless that she contemplated jumping off a balcony.

I'm now 23, and I've had three major depressive suicidal downswings that required intense therapy and

medication. Otherwise, I've managed. I never thought that my mental health was as important as my physical health. My mental health took a back seat until it compromised my physical health: I've been in a year-long battle with severe depression.

I've been doing intense therapy, working with my medical team and with my loved ones. If you've ever dealt with depression, whether situational or chronic, you know what it feels like. I tend to have more bad days than good ones. Even when I'm happy, this dark barracuda-type monster inside me eats at that happiness, and my head is filled with darkness. It's not something I can control. This downswing didn't happen overnight or over one thing. It was systematic. Shortly after I received my second kidney transplant, my life turned around. I'd gotten to that magical point, gotten the gift I'd waited so long for. I turned 21 a month later, and two months after that I was in a relationship. At the same time, I knew that it wasn't enough. A week after I left the hospital, my beloved cat died. Months later, my wonderful great-grandmother, who'd been my inspiration, also passed away.

But at the same time, I was right where I belonged in life. I was becoming the kind of adult I could be proud of. (In many ways, I still am.) But things just didn't add up.

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YOUR BEST CHANCE FOR TRANSPLANT

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THE COMMITTEE IS IN SESSION

by Lori Hartwell

I've had to undergo two surgeries in the past 6 months. One was an emergency hysterectomy: My gynecologist found a tiny spot of cancer and said that if I acted quickly, he could take care of it and I wouldn't have any further complications to deal with. The second surgery was a total hip replacement that was on my to-do list for when my schedule was free. Yeah, right! I was clearly in denial over how much hip pain I was experiencing. When it started to wake me from a sound sleep, I knew that I had to schedule the surgery.

But I was angry that I had to deal with yet more health issues! Would I ever get a break? I was upset that I had to relinquish control and sign the consent papers. The critic in my head (I fondly call it "the Committee") was cranking out questions at warp speed. What if my kidney is damaged? What if I can't walk afterward? What if I get an infection? How am I going to deal with the pain and the recovery process? What if they find more cancer? Will I be able to fulfill my obligations?

The list went on and on. Bottom line: I don't want to be a burden to anyone. I've learned that the best way to quiet the Committee is to talk to a good friend or write about what I'm feeling. Doing both is ideal. When I communicate about the emotional

upheavals that are taking up space in my head, my anxiety often subsides, and I can then focus on what I have to do and prepare for a speedy recovery or whatever comes next

Pick Up the Phone. When I knew that I had to have surgery, I started calling friends who had these same types of surgeries. They told me their stories, explained what to expect, and gave me questions to ask the doctor. The more they talked, the quieter the Committee became. We're so lucky to have social media at our fingertips; if you post that you want to chat on the phone with someone who has had a particular procedure, your in-box will be full in no time.

Grab a Pen and Paper or Let Your Smartphone Do the Typing.

Don't over think it—just begin writing and the words will eventually come. Your words aren't for publication, so allow yourself the luxury of not being perfect. What works for me is to put one word that describes the emotion I'm feeling or the goal I want to tackle at the top of the page. Then I jot down all my thoughts on that topic.

This exercise lets me clarify what the Committee is actually trying to say to me and helps quiet the voice in my head. Also, we have this great invention called voice-activated text. I can talk

to my smartphone about what I'm feeling, and the words magically appear. This is a great way to jump-start your writing. There are a number of options for creating voice-activated text with your computer too. When I tried it many years ago, the text that appeared after I said something looked like gibberish. Today the software is so sophisticated that it requires only a few tweaks.

One of the best ways to become a better writer is to read good books. Bill Bryson, who wrote the nonfiction bestseller *Walk in the Woods*, is one of my favorite authors. He has the amazing ability to tell a great story.

Take Control of the Committee.

Life is too short to let the Committee in your head ruin your enjoyment of life. Talk to friends or write about your feelings. Vincent van Gogh said it well: "If you hear a voice within you say 'you cannot paint,' then by all means paint and that voice will be silenced."

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.

My Journey Through Chronic Illness and Depression

continued from page 1

I knew I was sad, but I figured that if I just kept going, the problem would resolve itself. I started getting anxiety attacks that increased to four or more a day. I ignored my body because I was convinced I could push through. I've battled worse, right?

Not quite. I failed to listen to my body. Anxiety attacks aren't trivial; they're your body's physical response to your feelings. I knew this, but deep down I felt ashamed and guilty that despite the gift of life and all these good things, I was still unhappy. I wanted control and perfection. I worried that my depression and inability to master my feelings would make people disappointed in me.

I simply never thought that my mental health was as important as my physical health. Before my transplant, I had to meet with a psychiatrist and was aware that transplant medication

can cause or exacerbate depression. But depression plays tricks on you; denial is one of them. It wasn't until my health was at risk that my doctors and I saw how bad things had gotten and depression came to the forefront. I was terrified of

“EVEN WHEN I'M HAPPY THIS DARK BARRACUDA-TYPE MONSTER INSIDE ME EATS AT THAT HAPPINESS”

food. It often made me feel sick to my stomach. My reaction was, “If I don't eat, I won't be sick.” When I got blood work done, my panic attacks were unmanageable. I have problems with my veins, and drawing blood is always a production. All of this left me feeling depleted and completely hopeless. I often asked myself, “Why am I still here? I wish I could just fade away.” Those thoughts became more frequent and more immediate, turning into, “How can I put this into action?”

That's when depression became an issue. Right now, I'm still dealing with it. I'm turning shame and guilt into positivity. It's taking all I have to let go of my fears and walls, to reach out and ask for the help I so desperately need. When I think about it like that, I can't see it as a weakness any more. I see it as self-preservation—self-care. I have to treat it as I would a physical issue.

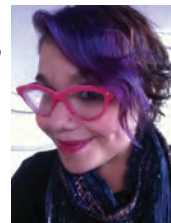
I also practice Dialectical Behavioral Therapy. I meditate; I do my best to focus on even the smallest amount of positivity that enters my day. I take time to care for myself and listen to my body, resting when I need to

or just reading a book. I'm making social changes in the form of deciding whom to spend time with and making my needs and boundaries clear. This sometimes means that I have to step away from people who will compromise my mental well-being. I let the people in my life know what my needs are and what they can do to help. (Sometimes, it's simply meeting up with a friend for a cup of tea or dinner or ordering in with my partner and watching a movie.) Sometimes it's asking for an encouraging word, because we have to hear that we're needed, that we matter.

As for self-esteem, I'm learning the difference between selfishness and selflessness and trying to understand that I can't please everyone all the time. I no longer buy into preconceived social ideas and take pride in living my life. I refuse to be ashamed or put down. No one has the power to make me feel inferior. I'm confident in the people in my life and mostly in myself, because at the end of the day, I have to love myself.

To others dealing with depression, I want to say that it will trick you into believing that it's hopeless. It's not. Remember that you matter; you mean something. And, most important, remember that “if you're going through hell, keep going.”

Michelle Kats was born in 1989 with birth defects. She had a transplant in 2001 that lasted until 2004; after six years on hemodialysis, she received her second transplant in 2010. A long-time patient advocate and disability activist, she lives in Boston.



**Where the Kidney
Community Connects**

Got Questions?
Need someone to talk to?
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The Kidneyspace.com
forum is a program of
Renal Support Network.



EMBRACEHOPE JEWELRY by lori hartwell

Everyone is always grateful to receive a second chance. When it comes to receiving the “gift of life” a second chance has new meaning. RSN celebrates all the people who give the greatest gift by donating an organ to those in need. Our premiere Second Chance collection, (Ann, Kathleen and Remember Me) is dedicated to Ann Lopez, Kathleen Hostert (living donors) and all deceased organ donors.



Second Chance COLLECTION

Visit the EmbraceHope page on our website to see the full collection.

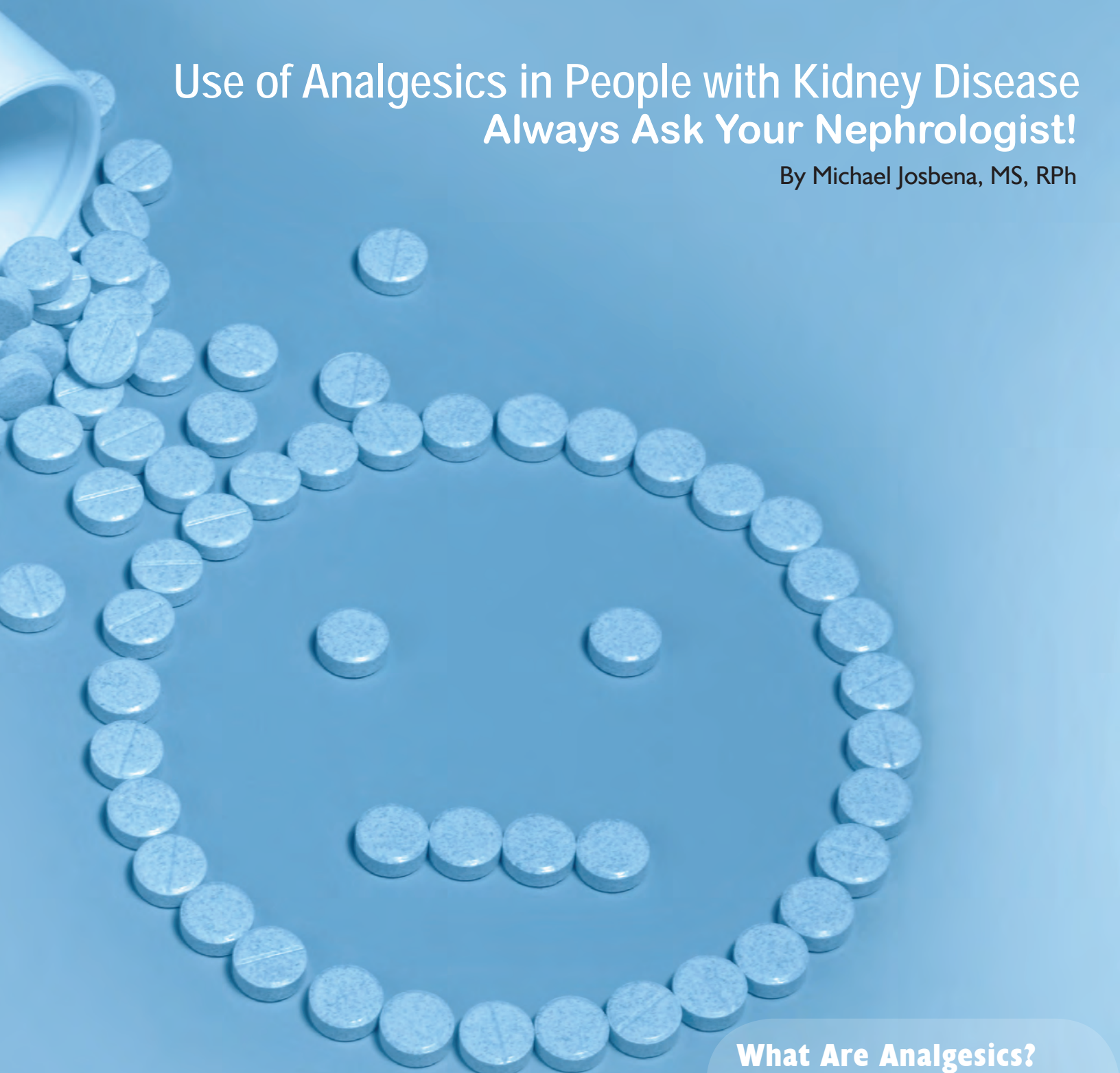
Kidney Heart Earrings \$15 Kidney Chain Link Earrings \$20
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For more information
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Use of Analgesics in People with Kidney Disease Always Ask Your Nephrologist!

By Michael Josbena, MS, RPh



What Are Analgesics?

Analgesics are medicines that are used to treat a variety of ailments, including pain, fever, inflammation, headaches, arthritis, and menstrual cramps, to name a few. There are many different types of analgesics. Some require a doctor's prescription, while others are available over-the-counter without a prescription.



Michael Josbena, MS, RPh has developed educational materials for individuals with kidney disease for over 25 years. He is the president of Wordsmiths Health Communications.

I Have Kidney Disease, So What Do I Need to Know When Choosing an Analgesic?

Many analgesics should not be taken by people with kidney disease. This includes people who have reduced kidney function, who are on dialysis, or who have had a kidney transplant. Always check with your nephrologist or advanced practice nurse before you start taking an analgesic. You should also check with your nephrology team when you receive a prescription for an analgesic from a doctor other than your nephrologist or when you are thinking about taking an over-the-counter medication.

Which Over-the-Counter Medications Could Contain Analgesics?

Many people incorrectly assume that over-the-counter medications are harmless. This is definitely not true, and many analgesics that can be purchased without a prescription can be harmful to people with kidney disease. The tablets and capsules used to control pain are the most obvious ones. But many other common products—including cough, cold, and allergy preparations—often contain an analgesic. Also, topical creams and gels used for ailments such as joint pain often contain an analgesic. Even though you apply these creams and gels to your skin, some of the analgesic can be absorbed into your bloodstream, so these preparations should not be used unless they are recommended by your nephrology team.

Are There Some Analgesics That Are Better Than Others for People with Kidney Disease?

Determining which analgesic is best depends on a variety of factors, such as why you need to take it, which other medications you take, and whether you have a disease or condition in addition to kidney failure. Again—avoid all analgesics until you have checked with your nephrology team. That being said, some analgesics are definitely more harmful than others. People with kidney disease should generally avoid nonsteroidal anti-inflammatory drugs (NSAIDs), a group of low-dose over-the-counter pain relievers, unless they are prescribed and carefully monitored by a nephrologist. Common generic names for these drugs include ibuprofen, ketoprofen, and naproxen. Some physicians recommend acetaminophen for occasional use by people with kidney disease, but it, too, can be harmful—the dose might need to be titrated, and it should not be used over the long term except under the supervision of your nephrology team. For more severe pain, physicians might consider the use of opioid drugs, which require a prescription. Some of these medications are typically avoided in people with kidney disease (examples include codeine, meperidine, and propoxyphene). Physicians sometimes prescribe other opioid drugs such as methadone and fentanyl for people with kidney disease, but careful monitoring and dose reductions are often necessary. Remember that analgesics are generally intended to be taken for only a short time. Further, the analgesic or the dosage that you took last year after talking with your nephrologist might not be appropriate today.

Are the Kidneys the Only Part of the Body That Can Be Negatively Affected by Analgesics?

Like many medications, analgesics are associated with a wide range of potential side effects on different parts of the body. For example, improper and/or long-term use of some analgesics can lead to gastrointestinal ulcers and bleeding, while others can lead to addiction. Analgesics may also need to be used cautiously in people with heart disease, liver disease, or high blood pressure. Also, analgesics could affect, or be affected by, the other medications you take. It is important that you ask your nephrology team how the use of a prescription or over-the-counter analgesic could affect the doses of your other medications.

The Bottom Line

It is impossible to review in this short article all of the available analgesics, their possible side effects, and their use in people with kidney disease—especially since they need to be individualized depending on your particular situation. The most important thing to remember is that use of all analgesics—whether prescription or over-the-counter—needs to be discussed with your nephrology team. Your discussion should include an assessment of which analgesic is best for you at this time, what the recommended dose is, how often the drug should be taken, how many days you should take it, when to call your nephrology team if you experience problems or side effects, and whether any laboratory tests need to be performed while you are taking the medication. Partnering with your nephrology team can help ensure that you use analgesics in a way that relieves your symptoms in the safest possible way.

Oh No! Not SHINGLES

By Linda Oakford

I woke up one morning and felt a slight burning sensation on my stomach. When I went to take a shower, I noticed a strange rash that ran in almost a straight line down my trunk, but only on the right side. I wondered whether it might be shingles, so I immediately did an online search. Sure enough, I found several pictures that looked just like my rash.

I called my doctor, who said to come to the office immediately. I was worried that this would affect my kidney transplant or take forever to heal, since I take immunosuppressants. After examining me, the doctor confirmed that it was indeed shingles and prescribed an antiviral medication. I wanted to learn what I could about my condition, so when I got home, I went online and found www.shinglesinfo.com.

I learned that shingles and chickenpox are caused by the same virus (the varicella zoster virus). Once you've had chickenpox, the virus lies dormant in your body. It can re-emerge later as shingles, possibly because your immune system has been weakened. The risk of developing shingles increases with age.

It's important to recognize the rash so that you can be treated quickly. Shingles can appear anywhere, but the rash most often occurs in a band or strip on one side of the body. It can also appear on one side of the face, in the area around the eye and the

forehead. For some people, the first symptom is pain, tingling, or an itchy feeling on a specific part of the skin; the rash then follows.

The pain associated with shingles can be severe. It can come and go or be constant and so intense that even a slight breeze against the skin can cause discomfort.

Unfortunately, there's no cure for shingles, although there are things you can do to relieve the pain and itching temporarily. See opposite page for more information.

“Once you’ve had chickenpox, the virus can re-emerge later as shingles”

One out of every four people who get shingles will experience complications in the form of secondary bacterial infections, long-term pain, permanent scarring, vision impairment, or Ramsay Hunt syndrome (a neurological disorder that affects the facial nerves and can cause hearing and balance problems).

I learned from the Centers for Disease Control and Prevention web site that there's a shingles vaccine (Zostavax) recommended for people aged 60 and older. There's no maximum age for getting this vaccine, which is

administered only once. The CDC doesn't recommend its routine use in people younger than 60, although the Food and Drug Administration has approved the vaccine for people between 50 and 59. Studies have shown that more than 98% of Americans 40 and older are at risk for shingles because they've had chicken pox, even though they might not remember getting it.

The CDC website also noted that there are some people who should not get the vaccine. (See list on opposite page.) My doctor did not think the vaccine was a good option for me as I am a transplant recipient.

I learned that shingles can last up to 30 days, and I found that to be true in my case, although the rash didn't blister because the infection was caught early. I followed the advice of my doctor. I took the medication, wore loose clothing to keep from irritating the rash, and used calamine lotion to relieve the burning. I didn't experience the fierce itching that many of my friends did, although my skin was very tender to the touch. While shingles is no fun, early detection is the key to a quick recovery.

Linda Oakford was diagnosed with PKD in 1985 and received a transplant from her girlfriend in 2001, before she had to undergo dialysis. She has been working for Renal Support Network since 2006 as a Patient Coordinator and a HOPEline Operator.



The CDC advises against a Shingles Vaccine to anyone under 60 or with the following conditions:

- 1** People who have had a life-threatening or severe allergic reaction to gelatin, the antibiotic neomycin, or any other component of the vaccine
- 2** People who have HIV/AIDS or another disease that weakens the immune system
- 3** People who have had cancers that affect the bone marrow or lymphatic system, such as leukemia or lymphoma
- 4** People who have been treated with drugs that affect the immune system, such as steroids, or who have received cancer treatment in the form of radiation or chemotherapy
- 5** Women who are or who might be pregnant

It's important to recognize the Shingles rash so that you can be treated quickly.



Raised red bumps and blisters caused by the shingles virus.



Mild case of shingles rash on the side of the body.



Severe case of shingles rash on the side of the body.

To relieve the pain and itching temporarily:

- **Apply cool wet compresses**
- **Take oatmeal baths**
- **Use soothing lotions such as calamine**
- **Keep the affected area exposed to the air**
- **Wear loose-fitting clothing**
- **Take antiviral medication as prescribed by your doctor**

Resources:

www.shinglesinfo.com.

Centers for Disease Control and Prevention (CDC):

www.cdc.gov/vaccines/vpd-vac/shingles/default.htm

HOPEline



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HOPEline también está disponible en español.



Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2013

Would provide for extended Medicare coverage of the drugs all recipients must take every day to prevent rejection.

H.R. 1428: To amend title XVIII of the Social Security Act to provide for extended months of Medicare coverage of immunosuppressive drugs for kidney transplant recipients and other renal dialysis provisions. Reintroduced by Rep. Michael Burgess (TX) and Rep. Ron Kind (WI)

S. 323: To amend title XVIII of the Social Security Act to provide for extended months of Medicare coverage of immunosuppressive drugs for kidney transplant recipients and other renal dialysis provisions. Sponsored by Sen. Richard Durbin (IL) and Sen. Thad Cochran (MS)

Those who receive kidney transplants must take immunosuppressive drugs for the life of the transplant to prevent the body from rejecting the organ. Currently, as part of the End-Stage Renal Disease benefit, Medicare pays for most kidney transplants, but covers drugs for only the first 36 months after transplantation. After that, recipients must pay for these drugs out-of-pocket or depend on coverage from private insurance or public or pharmaceutical assistance programs. If the patient qualifies because of age or disability, however, Medicare has no time limit on payments for drugs. The Comprehensive Immunosuppressive Drug Coverage for Kidney

Transplant Patients Act of 2013 would provide for extended Medicare coverage of the drugs all recipients must take every day to prevent rejection.

Immunosuppressive drugs are expensive, but the alternative is even more costly. Medicare spends \$17,300 per patient per year on antirejection drugs to maintain a kidney transplant, but if the transplant fails and the person returns to dialysis, the cost is in excess of \$68,600 per year. And because dialysis can be so physically draining, quality of life often suffers as well. Please contact your elected officials and ask them to sign on as co-sponsors of this bill.

Are you concerned about policies and news affecting people with kidney disease?

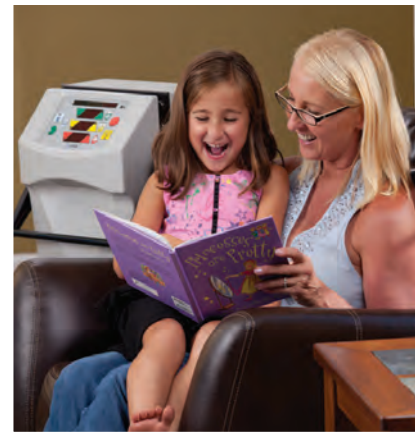
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What did
you learn from
this issue of
Live&Give?

Take our Quiz and find out!

Send us your completed quiz to be
entered into our prize drawing!

1. Currently, how long does Medicare cover transplant medications?

- A. 5 years
- B. 36 months
- C. Lifetime

2. The name of the organization that facilitates living donor kidney transplant swaps.

- A. Renal Support Network
- B. Center for Disease Control
- C. National Kidney Registry

3. Which is NOT an example of analgesic?

- A. Topical creams and gels used for joint pain
- B. Cough, cold, and allergy medications
- C. Blood pressure medications

4. Ask questions, share information, or connect with the kidney community at this forum:

- A. kidneyspace.com
- B. cdc.gov
- C. kidneyregistry.com

5. What is a symptom of shingles?

- A. Dizziness
- B. Rash
- C. High blood pressure

6. What is a strategy that Michelle Kats used to battle depression?

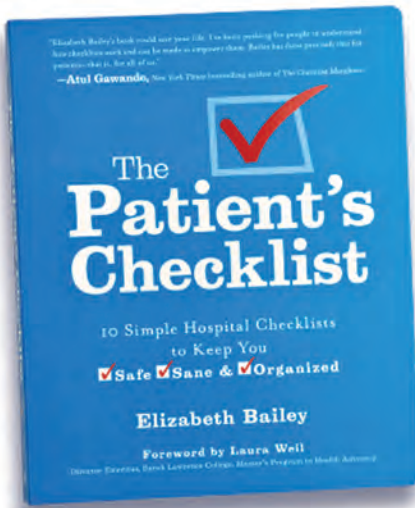
- A. Avoid friends and family
- B. Eat more fatty foods
- C. Dialectical behavioral therapy

7. What can help prevent medical errors in the hospital?

- A. Take medication list
- B. Bring teddy bear
- C. Listen to iPod

Send your responses to RSN (mail, fax or email) by August 1, 2013 to participate in a drawing for RSN's new book *Hope, Inspiration & Wisdom – A Treasury of Thoughts on Coping with Kidney Disease*. Ten winners will be chosen and announced in the next issue.

See RSN address on page 14



The Patient's Checklist: 10 Simple Hospital Checklists to Keep You Safe, Sane & Organized By Elizabeth Bailey

The Patient's Checklist by Elizabeth Bailey is the perfect book for people who are hospitalized or facing hospitalization and their family and friends. She has broken her book into 10 categories: Before You Go, What to Bring, During Your Stay, Master Medication List, Daily Medication Log, Daily Journal, Discharge Plan, Insurance, Doctor Contacts, and Family & Friends Contacts.

Hospitals are overwhelming places made up of many different departments running on very high tech systems at an incredibly fast pace. People enter the hospital because they're ill or must undergo tests or surgery. When they're not at their best, they need to deal with procedures, doctors, medications, and sleeping in a not-so-comfortable bed. Completing the checklists in this book can help.

People with chronic kidney disease tend to be hospitalized more often than average and have learned the hard way that hospitals aren't free from critical mistakes. It's especially important that you and your loved ones know which medications you take and why you take them in order to avoid drug interactions or terrible side effects. As Bailey puts it, "A hospital patient, on average, is subject to one medication error per day." Everyone wants patient-centered,

quality hospital care. Unfortunately this doesn't happen automatically; it does take a village and/or an advocate. Patients always need an advocate: a parent, friend, spouse, or child who acts on their behalf to help them get the care they need. Having someone else take a powerful proactive role helps keep patients safer. Passivity can be dangerous, and communication is key. Asking questions is essential so people can make informed decisions about their care.

"Armed with the checklists in this book, an empowered patient will receive safe care"

It's important to remember that although hospitals run around the clock, the staff doesn't. Shift changes can be problematic. Day nurses should explain all relevant events and details to night nurses, but things sometimes fall through the cracks. Writing in a daily journal, or having a friend do so, is vital because documenting as much

as possible can help the nurse or the doctor assess how well a particular treatment is working.

Hospitals provide medical treatment, but they rarely have time for comfort-related issues. True healing often comes from compassionate friends and family who are concerned with a patient's quality of life. They observe how their loved one is eating or sleeping, what the mood and pain levels are, whether the room is clean, and whether nurses change their gloves, for example, and act on that information.

Bailey stresses that we must always remember the person first and the patient second. No one should be treated as a nameless body in a bed, but rather as a human being with thoughts and feelings. She hopes that armed with the checklists in this book, an empowered patient will receive safe care, administered with kindness, during his or her hospital stay.

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 Renal Support Network and The Kidney Association of South Florida where she lives with her husband Steve.



2013 Essay Contest

2013 ESSAY THEME

“provide
an example
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maximum
750 words

deadline
august 1st
2013

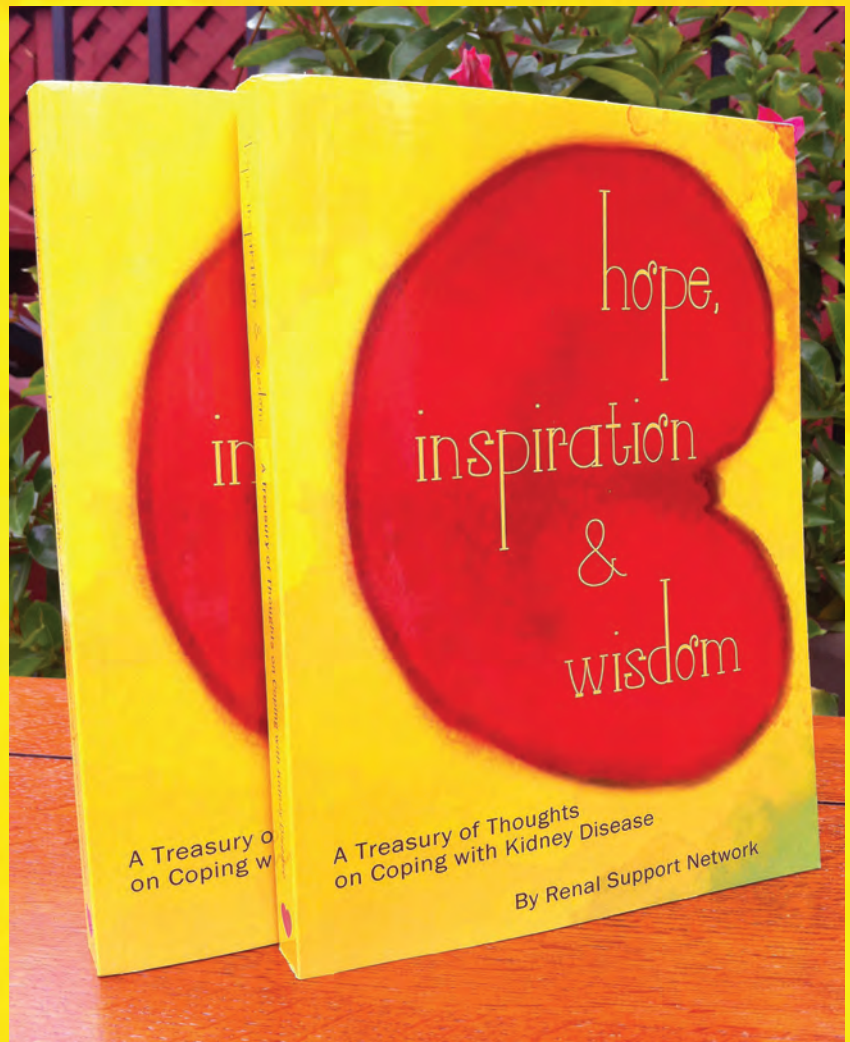
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CHRONICALLY HAPPY: *JOYFUL LIVING IN SPITE OF* *CHRONIC ILLNESS* – BY LORI HARTWELL

The insightful, often humorous, and touching story of how Lori chose to live life rather than succumb to its obstacles. She chronicles her approach of taking simple, logical steps in order to realize one's dreams. Available at amazon.com and RSNhope.org.

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RSN is thrilled to bring you this commemorative book to inspire hope in people with kidney disease. This is a collection of 10 years of winning essays from RSN's Annual Essay Contest.

In this publication you will find a collection of 30-plus thought-provoking essays by the first, second and third place winners of the Annual Essay Contest. Thousands of essays have been submitted since the contest began in 2002.

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Live & Give

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*If you have a change of address
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MISSION

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patient-run nonprofit organization
whose mission is to identify and
meet the non-medical needs of those
affected by chronic kidney disease.

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What is RSN?

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.

Write for RSN

Whether you're an established writer or simply someone who has a story to tell, we'd love to hear what you have to say! Whenever possible, RSN obtains patient-authored articles that we post on our website or publish in our newsletter *Live&Give*. We're looking for patient profiles or success stories, lifestyle tips such as how to cope with dietary restrictions or how to tell the person you're dating that you have a peritoneal dialysis catheter, and renal-friendly recipes. Find complete guidelines at RSNhope.org. Click on Health Library in the sidebar, then Author Guidelines.

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Delicious!

This kidney-friendly cookbook is proudly sponsored by Abbott Renal Care and favorably reviewed by Renal Dietitians, a dietetic practice group of the Academy of Nutrition and Dietetics.



The American Association of Kidney Patients (AAKP) is now taking orders for its new recipe book *AAKP Delicious!* This is the perfect gift for that special someone in your life that is looking for healthy, kidney friendly meals.

These 16 simple but delicious recipes are designed to fit into any kidney friendly diet. The book contains recipes for pastas, seafoods, meats, desserts and soups. Place your order today by calling 1-800-749-2257 ext 3. The cost is just \$10. Supplies are limited, so take advantage of this opportunity.



Service to those affected by chronic kidney disease

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