Dare I say that “four-letter word?” Do I have the willpower to claim that all-empowering word as my own? Well-meaning friends, family, and even healthcare professionals may be afraid to use it, as if the mere idea is taboo. To even think it, much less say it out loud, is too risky. After all, it may not be true.

When I dialyzed at the clinic or went in for my labs, I heard the fear in the voices of other patients. None of them dared to use that four-letter word. It was unimaginable, unspeakable, unclaimed.

As I wondered whether it would always be this way, I glanced again at the announcement on the wall: “Coming soon: The Renal Support Network will be starting a kidney support hotline run by kidney patients.” Finally, someone out there wasn’t afraid to say that four-letter word! I whispered it quietly to myself as I left the clinic and headed for home: “Hope.”

Okay... so maybe this story line is a little dramatic, but the message behind it isn’t. As someone with kidney disease, well-intentioned but negative people surround me every day. As soon as people hear that you...
As a child, Bob Bell loved to build sandcastles. He spent as much time as he possibly could at the beach, creating these complex structures. As he grew older, he found that he was quite good at building sandcastles. In fact, crowds of barefoot onlookers in bathing suits would stand for hours watching him work. But he eventually took a “normal” job and stopped building sandcastles.

When you’re diagnosed with chronic kidney disease, you may go through a period of adjusting to what will be a different lifestyle from the one you’re used to. During that reorientation phase, you might feel a bit out of it or disconnected from the rest of society, and you may even feel that you’ve lost the ability to pursue your dreams.

When you finally feel ready to start making some new goals and plans, you might experience a surge of enthusiasm. The ideas and plans sometimes come to you like shooting stars, leaving your head spinning!

It’s important to have a lot of dreams you want to pursue. However, it takes hard work, and lots of it, to make those dreams a reality. Dreams are most often accomplished by tackling one goal at a time, making a realistic game plan, and giving that vision your undivided attention until you’re finally headed toward your goal.

Pick realistic dreams. Given your talents and resources, what can you realistically accomplish? You can’t say, “Oh, I’d like to go the moon someday,” without being in an astronaut training course. Whatever a client desires, Bob makes it happen, all the while following his heart’s desire and living his dream.

Do you have a crazy idea or dream? Don’t let your struggle with chronic kidney disease rob you of it. Fulfilling your dreams may take a little longer, but set your feet on the path and start the journey.

Never forget that life is an adventure. Your life is your adventure. Go create a life that dreams are made of—build your own sandcastle!
increase awareness about chronic kidney disease (CKD), helping patients learn self-management skills, and exploring the barriers to different treatment modalities. Since there is no existing law to increase the reimbursement rate for dialysis treatments to keep up with inflation, the legislation would also link the need for an annual update mechanism for the end-stage renal disease (ESRD) composite rate with an improved quality system.

Late in the session, both the House and Senate passed legislation to reauthorize the health program for low-income children. The House version is the Children’s Health and Medicare Protection Act or CHAMP (HR 3162), and the Senate version is the State Children’s Health Insurance Program or SCHIP (S 1893). Provisions from the KCQEA were included in the CHAMP bill, along with other Medicare issues. As a result, these children’s health bills could potentially have a major effect on quality of care for patients with kidney disease.

Some of the money to pay for the children’s health care program would come from savings in the Medicare program, effectively pitting the needs of children against those of their grandparents. One measure that helps the children’s health package and saves Medicare money over the long term is an expansion in the Medicare Secondary Payer Provision. In other words, for patients under age 65, private insurance would remain a dialysis patient’s primary insurance for a longer period of time.

Most critically, the CHAMP bill includes a bundling system for the Medicare composite rate that incorporates the administration of certain medications and services—items that are now billed separately—into the dialysis reimbursement rate and decreases the rate by four percent. This loss of funding would most certainly impact quality of care, and not for the better. The Senate bill currently contains no ESRD program amendments, but these two bills must be reconciled into a single piece of legislation to be presented to the White House before the current program authorization runs out on September 30.

Another bill introduced in the House—the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients (HR 3282)—would extend the Medicare payment for transplant medications beyond the three-year cut-off for all transplant recipients, not just those over age 65 and those who are disabled. A Senate companion bill still needs to be introduced.

Finally, Congress was not the only potential source of change. The Food and Drug Administration (FDA) scheduled a hearing on September 11 to address the administration of Erythropoietin Stimulating Agents or ESAs (Epogen, Aranesp, and Procrit) in people with CKD. There has been significant controversy since the FDA issued a black box warning on the use of ESAs in March, and the agency’s recommendation could have irreversibly impacted the quality of life for people with kidney disease.

Fortunately, the advisory committee clearly heard the clinical results presented and took to heart the impassioned testimony of Lori Hartwell who spoke on behalf of patients. Instead of recommending stricter hemoglobin limits, the committee voted 14-5 to keep current guidelines, thus allowing physicians to continue to prescribe these medications based on a patient’s individual circumstances.

All of the proposed legislative changes have the potential to affect the quality of care that patients receive. Please take a moment to contact your senators and representatives and ask them to support those bills that best address the needs of patients with kidney disease and reject those that would trade quality healthcare for other priorities. For more information, please visit the Advocacy pages at RSNhope.org.
**HANDWASHING**

**Little Thing, Big Results**

Experts agree that handwashing/hand hygiene is the single most important measure in preventing the spread of infection. The Centers for Disease Control and Prevention offers clear guidelines that we’ve all heard repeatedly:

- When washing your hands, use warm running water, soap, and friction for a minimum of 20 seconds.
- Alcohol-based (greater than 60 percent) gels can also be used, but only if the hands aren’t visibly soiled. All hand surfaces should be cleaned with a generous amount of sanitizer.
- Wash your hands after coughing, sneezing, and blowing your nose. Wash them before and after preparing food, after trips to the bathroom, and after handling pets.
- Wash your hands after contact with bodily fluids—yours or an other person’s.

Besides hand hygiene, here are other simple precautions:

- Cover your mouth and nose when coughing or sneezing.
- When blowing your nose, use tissues once and discard them immediately. Don’t stuff them in your pocket. (Ditto for wiping the kids’ noses.)
- Keep your hands away from your face and mouth. (This is easier said than done.)
- Avoid close contact with people who are ill. Malls and theaters are crowded venues that are sometimes worth bypassing.
- Avoid sharing toothbrushes, towels, and similar items. Maintain good personal hygiene.

**Reference**


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**To Your Health**

**Little Things Mean A Lot**

**Preventing Infection**

by Denise Eilers, RN, BSN

Has anyone not seen a television exposure about germs lurking everywhere in our homes and healthcare facilities? Lately, we’ve been bombarded with data about superbugs with puzzling initials. Some people react to this barrage of information and advice with a mental “so what?” while others become positively compulsive about cleanliness.

Going to either extreme isn’t the answer. However, incorporating some little commonsense things into our daily life can make a big difference, and being vigilant in a healthcare setting can pay huge dividends.

**Back to Basics**

Since the cold and flu season is just around the corner, it might be helpful to recall some of the basics we all learned in grade school.

Not all microorganisms are bad and cause infection. Some are vital for bodily functioning. The harmful microorganisms (pathogens) that can cause infection we usually lump together and call “germs.”

Germs need a way to get into our bodies and, once there, they also need somewhere conducive to their growth. They love a warm, dark, moist environment—the nose, mouth, lungs, or a wound. Any natural opening (mouth, nose) or artificial opening (accidental injury, surgical wound, intravenous site) is a potential spot for germs to enter the body.

To get from one person to another, germs need transportation. They can be spread directly from one person to another or indirectly by touching contaminated objects.

Certain factors like age, nutrition, fatigue, stress, and other diseases make a person more susceptible to infection. Obviously, that’s especially true for dialysis and transplant patients. See the sidebar for standard precautions you can take to minimize your risk.

**Healthcare Settings and Hospitals**

Hand hygiene is doubly important in healthcare settings. When you’re in the hospital, you’re already ill and exceptionally vulnerable. You wash your hands, so demand that your caregivers do the same. Don’t let anyone, including a physician, touch you if you haven’t seen that person wash or use a hand sanitizer. A conscientious healthcare worker never resents a reminder.

Caregivers must wear gloves whenever there’s a possibility of contact with bodily fluids. However, gloves are never a substitute for hand hygiene. Also, staff should remove gloves before leaving a room and re-glove when returning. No one caring for you should have fake, long, or polished fingernails. Those are perfect traps for germs.

If someone caring for you has a cold or is coughing, ask him or her to wear a mask. Friends and relatives should never be left out of the loop. Request that they wash their hands often and take other precautions.

If potential visitors are ill, ask them politely to phone or send a card and stay away until they’ve recovered.

Also, with few exceptions, each patient should have his or her own equipment. Taking items from room to room (or station to station in dialysis units) is a perfect way for germs to hitch a ride!

Workers should never shake bed linens or put them on the floor. Lin-
Got some questions about kidney disease? Want to chat with others who share your experiences as a kidney patient? Then log onto KidneySpace, an online discussion forum for those affected by kidney disease, their families, healthcare providers, and the general public.

KidneySpace—created by the Renal Support Network (RSN)—provides opportunities for sharing health and medical lifestyle information, fostering personal and social connections, and learning about what’s new and different in all of RSN’s programs. With over 100 members since its inception in mid-August, it’s already proving a popular meeting ground!

Registration is free, and members can participate in discussions that not only include topics such as dialysis, transplantation, and current kidney-related news, but also “Just for Fun,” and “For the Love of Pets.” After all, those with kidney disease are real people who have a life outside of their illness!

Members are also invited to share personal stories as well as respond to questions from those who have just been diagnosed with kidney disease. A product of patients’ experiences, the discussion forum is one of several programs founded by RSN to empower kidney patients by providing information, support, and hope.

The goal of KidneySpace—and all of RSN’s programs—is to enable patients to advocate for themselves on every level: personally, locally, and nationally. Moderated by members of RSN, KidneySpace upholds priorities of respect, confidentiality, inspiration, education, and correct information.

This is just one more way that RSN is continuing to reach the kidney community—building community programs led by patients.

Go to www.KidneySpace.com and become a member today. You can make a difference!

To Your Health
Continued from page 4

Patients must become informed partners in their care.

If you can’t turn and reposition yourself, nursing personnel should do it at least every two hours to relieve pressure over bony areas where bedsores can form. Besides, this movement also helps prevent mucus from pooling in the lungs. Germs love mucus.

Respiratory infections that result from inactivity can be prevented by regular deep breathing and coughing. If coughing hurts, “splint” your chest by hugging a pillow while you cough.

Surgical wounds are a terrific breeding ground for infection. Know how often your doctor wants dressings changed. They should be kept clean, dry, and intact. If anything about a wound area feels or looks different, let someone know.

Partnership and Advocacy
No one can live in a sterile bubble, but much needless suffering and death can be avoided by implementing simple measures to control infection. To accomplish this, patients must become informed partners in their care.

If something doesn’t seem quite right, speak up. If you have a question, ask. If you don’t understand the explanation you’re given, get immediate clarification.

Since your well-being and overall health depend largely on preventing infection, you can’t afford to be passive. Never forget—your best advocate is always YOU!

Denise Eilers is both a healthcare professional and family member. Her husband Jerry was on traditional (three days per week) home hemodialysis from 1980 until his death in October 2004. Denise is a volunteer with Genesis VNA Hospice in Davenport, IA, where she resides. She also teaches nursing fundamentals at United Township Area Career Center in East Moline, IL.
FACES OF THE HOPELINE

Offering Peer Support, Experience, Strength & Hope

An illness is too demanding when you don’t have HOPE!
Below: Trainers Cecilia Torres-Correa, RN, BSN (left photo) and Arlene Antonoff, LCSW (right photo) instruct trainees on how to address caller’s questions.

HOPEline Training
August 2007
Los Angeles, CA

A compassionate operator is waiting for your call!
Hours: Monday-Friday 10:00 A.M - 8:00 P.M. (Pacific Time)
I never thought the day would come. A transplant! Me! I’m a kidney transplant recipient!

Sarah is the most amazing woman I’ve ever met. She and I attend a small Church of Christ and we consider ourselves sisters in Christ. Well, for two years this “sister” had been after me to test her as a donor.

Over the period of two and a half years, seven other potential living donors had gotten tested but all were ineligible for various reasons. My doctors recommended I accept nothing less than a 4-antigen match since I had the luxury of waiting for something better. Many deceased donor kidneys were less than that, so I continued to look for a living donor. A 6-antigen match is considered a perfect match.

Every time one of my donors failed the medical testing, Sarah would ask me, “When are you going to test me?” When I asked why she wanted to do it, she said simply, “God gave me two good kidneys and you need one.”

Of my prior donors, four were family members and three were unrelated. It’s predictable and easy to grasp when a family member wants to donate a kidney, but it’s still uncommon to give a kidney to someone who is not related. Making such a donation takes a very special person, and here was this unrelated angel who just wanted to share. How humbling is that?!

However, because she was only a 2-antigen match, I hesitated to accept her gift until I talked to every medical person who knew anything about transplants. Without exception, each one patiently and consistently explained to me that any living donor, even one with a zero-antigen match, was a good donor—so I shouldn’t hesitate.

Once I was finally able to absorb this information, then I got excited. So we set the date for June 18, 2007, and I now have a new kidney!

Our surgery went unbelievably well. Sarah and I were told that we broke a record... in fact, several records.

From the time a kidney is removed to the time it’s placed in the recipient can be anywhere from 30 to 60 minutes, which means that the kidney may be placed briefly on ice while the surgical team preps it for transplantation.

Well, Sarah’s kidney was so perfect that it took them only 13 minutes to transplant it! My surgeon was still scrubbing when Sarah’s kidney was ready, so her surgeon started on me and my surgeon ending up assisting.

The other record we broke was how well the new kidney worked. It dropped my creatinine level from 9.2 to 0.9 within the first 24 hours. Absolutely, perfectly normal! I told you it was unbelievable!

Every day gets better. Many people told me that I wouldn’t believe how good I’d feel afterward. I thought they were exaggerating, but they weren’t. I thought I was on an adrenaline rush. It finally dawned on me that this is what clean blood feels like.

Sarah has given me back my hope for the future. I have already sent out several applications so I can get back to work, and I can now become more involved in my volunteer activities. I hope to use my life to inspire other transplant and dialysis patients.

I’ll never be able to repay Sarah, but I can take responsibility for the care of her precious gift. Rest assured—that’s something I will do.
Transplant Coordinators
by Amy Wright

Waiting... We all know the feeling. Whether you’re waiting for your latte or for a phone call, it’s no fun. And when that phone call can mean the difference between life and death, being in the waiting stage can be a challenge, as those who need a life-saving organ transplant know all too well.

This wait is also very familiar to transplant coordinators. They, too, are hoping for a call. They, too, are waiting for the news that could mean life for someone special—a patient they’ve come to know.

Coordinators oversee patient care. Working with a team of specialists, the coordinator puts the candidate on the United Network for Organ Sharing (UNOS) list and continues to keep track of that person’s status. The coordinator gets to know the patient and many times goes the extra mile to help.

When the call comes that a donor has been identified, the transplant coordinator must quickly determine whether the organ is suitable for that patient, notify and organize the transplant team, and schedule the surgery.

Those who choose nursing as a career consider it a true calling. Transplant coordinators have a multifaceted job that they approach with a genuine commitment to provide their patients with the best possible quality of life. Mental and emotional demands are high. After 18 to 36 months, many coordinators will have experienced burnout. Yet there’s also dedication that stands the test of time.

After the transplant, the post-transplant team takes over managing the patient’s care. Yet the transplant coordinator doesn’t soon forget each patient fortunate enough to receive the gift of life. Connections were made between the coordinator, the patient, and the family members. Together they worked to maintain the patient’s health while they waited, and together they celebrate another successful transplant.

So whether you’re still waiting or have already received that important call, remember the transplant coordinators and the good work they do.

After 18 to 36 months, many coordinators will have experienced burnout.

Amy Wright is a caregiver to her father, who is currently awaiting a kidney/liver transplant. Amy is a University of California, San Diego (UCSD) alumna and a local REALTOR® in neighboring Rancho Santa Fe. She fills her free time with writing, giving donor awareness presentations to children under age 12, and helping to organize blood drives.

Options and Choices
by Dawn Dungan

I decided I wouldn’t like her right from the start
She couldn’t heal my body nor fix my broken heart
“I don’t want to live!” I yelled at her and cried
“How do you know?” she asked, “You haven’t even tried.”

“This is impossible, dialysis I just can’t do”
“You can do anything,” she said, “that you put your mind to”
“Not this, not this,” I defiantly replied
And then I knew she saw it—the fear that had been my guide.

She continued, “You have so much to offer, so much to give
You’re young and have a lot of life yet to live”
“I don’t see it that way,” I answered back
“My life is over; I’ve run out of track.”

Compassionately she offered, “Please give this a chance
Nothing in life is ever happenstance
Everything happens precisely for a reason
Sometimes it’s long term, sometimes just a season.”

This is where I draw the line in the sand
I’m ready to reach up and take God’s hand
I’m tired of living and I’m prepared to die
I just need to tell my family so I can say good-bye.

I think this choice is right for me, the other one is wrong
She came back at me bold and strong
“Then get everyone together and make sure they know
Your decision is not to stay here—your wish is to go.”

Oh how mad I got at her that day
Who did she think she was talking to me that way?
I’d never forgive her, that much I knew
I left her office muttering, “I never want to be like you.”

Two years in that dialysis chair came and went
Before I recognized the angel God had sent
She had been hidden from me due to fear and shame
But forgiveness freed me as I called on His name.

Oh Dear God how wrong I was about her
All the could-have-beens passed before me in a blur
I seized the opportunity to work with her in a class
Where I could tell everyone I had been so crass.

Now we’re working on a friendship of over four years
That has brought me joy instead of regretful tears
I pray she thinks of me at times in her life
That I believe can only be inspired from above.

Dawn Dungan is a kidney transplant patient who lives with her husband in Billings, MT. Throughout her 20 years with kidney disease she has learned many lessons about life, which she shares through writing and public speaking.
Dressing for Success

Continued from page 12

comments is a source of encouragement to me.

Recently, as I was reading Chronically Happy by Lori Hartwell, I discovered that she, too, emphasizes the importance of dressing up. Toolbox #5 on page 53 states, “Dress Up: To combat the temptation to get down and stay there I make it a habit to dress up occasionally or at least wear something besides my robe, sweats or other ‘icky’ clothes.”

I want to challenge everyone who feels depressed, disheartened, or discouraged to try these things:

Encourage yourself. Try meditation or prayer. Read good literature and it will expand your thinking.

Learn more about your illness. The more you understand, the more empowered you’ll become and the better equipped you’ll be to deal with challenges.

Talk to your healthcare team and to other patients to help reduce your feelings of gloom and doom and remind yourself that you’re not alone. You’ll have a stronger connection to others during your moments of weakness.

Finally, strive to dress better. When your appearance reflects your best, it provides you with an opportunity to encourage yourself.

Chances are, you’ll look better not only to others, but also to yourself. And that will help you to feel better too!

Jacqueline Bland is a 55-year-old dialysis patient who has lived with kidney disease since 2003. She enjoys being involved in her church, and she also serves as the patient representative of her dialysis clinic for ESRD Network 8. Recently she became involved in the Renal Support Network (RSN). She is an RSN HOPEline operator and has traveled to Washington, DC, with other patients from RSN.

SAVE THE DATE!

Sunday, January 20, 2008

The 9th Annual RSN Renal Teen Prom

Winter Elegance

Held at Notre Dame High School
Sherman Oaks, California
FREE ADMISSION
For kidney teens and a guest.
Registration required.

Make plans now to attend!
Details coming soon at RSNhope.org.

Chances are, you’ll look better not only to others, but also to yourself. And that will help you to feel better too!

Jacqueline Bland is a 55-year-old dialysis patient who has lived with kidney disease since 2003. She enjoys being involved in her church, and she also serves as the patient representative of her dialysis clinic for ESRD Network 8. Recently she became involved in the Renal Support Network (RSN). She is an RSN HOPEline operator and has traveled to Washington, DC, with other patients from RSN.

KidneyTalk!

A new half-hour show is uploaded weekly. All shows are available online 24/7. Also available as a podcast on iTunes.

Listen to KidneyTalk online at: RSNhope.org

With your hosts Lori Hartwell and Stephen Furst

Order CDs of KidneyTalk at RSNhope.org!
have kidney failure, they suddenly start feeling sorry for you and lamenting about what a raw deal you got. How many of you have had the same experience?

You know what? It’s not the end of the world! There’s hope for people with kidney disease. We can—and do—lead normal, productive lives. And for those of us who need a little encouragement from time to time, the Renal Support Network is ready and waiting to take our call!

A support line for kidney patients in need of someone to talk to is now up and running. It’s called the HOPEline. HOPE stands for “Helping Others Pursue Empowerment.”

Patients just like you and me answer each call—positive, energetic people who’ve been successful in taking back their lives while dealing with kidney disease.

When you call the HOPEline, you’ll connect to a fellow patient who understands what you’re dealing with. Knowing that your privacy will be respected, you can share your frustrations, disappointments, dreams, and questions with a person who has walked where you’re walking.

And your family and friends can also call and talk to someone who can help them understand what you’re going through—someone who cares and is willing to listen.

I’m excited about the HOPEline! Having a support system will help empower you and me to be actively involved in our care—not only our medical care but our personal lifestyle as well.

The goal of the HOPEline is to let those affected by kidney disease know that there’s hope for a successful kidney lifestyle.

Call the HOPEline. We’re here to listen, to support, and to empower. “Hope.” You can say it!

During the last few years, Christine Sanders has traveled around the country because of her involvement with Renal Support Network (RSN) and ESRD Network 16, lugging along her peritoneal dialysis machine wherever she goes. Her RSN activities include PEPP speaker, weKAN member, and HOPEline operator. At home, she spends time with her four-year-old goddaughter, attends church activities, and works in her garden.
Dressing for Success
by Jacqueline Bland, HOPEline Operator

We’ve all heard the term “dress for success,” but what does it have to do with those of us who are dealing with kidney disease?

Dressing for success brings to mind people striving for a better life. It doesn’t mean flaunting yourself, nor does it mean being vain. Dressing to look your best helps improve not only your appearance, but your attitude as well. And that leads to positive effects on life!

Living with a chronic disease can generate a lot of negative emotions, even depression. In my four-year struggle with end-stage renal disease, I didn’t acknowledge at first that not only was I feeling unwell, I was also depressed.

However, once I realized the importance of looking better, I found that I felt better about my condition. And feeling better empowered me to show concern for others. I began to talk with other patients and with the members of my healthcare team. People soon noticed the change in me. I began to receive compliments on how well I looked. Successful days followed as I challenged myself to always look better.

My most recent trip to Washington, DC, with the Renal Support Network was a prime example of how compliments have given me the courage to “keep on keeping on.” People remarked several times that I didn’t look sick or didn’t look like a dialysis patient. Hearing such compliments made me feel better about myself.