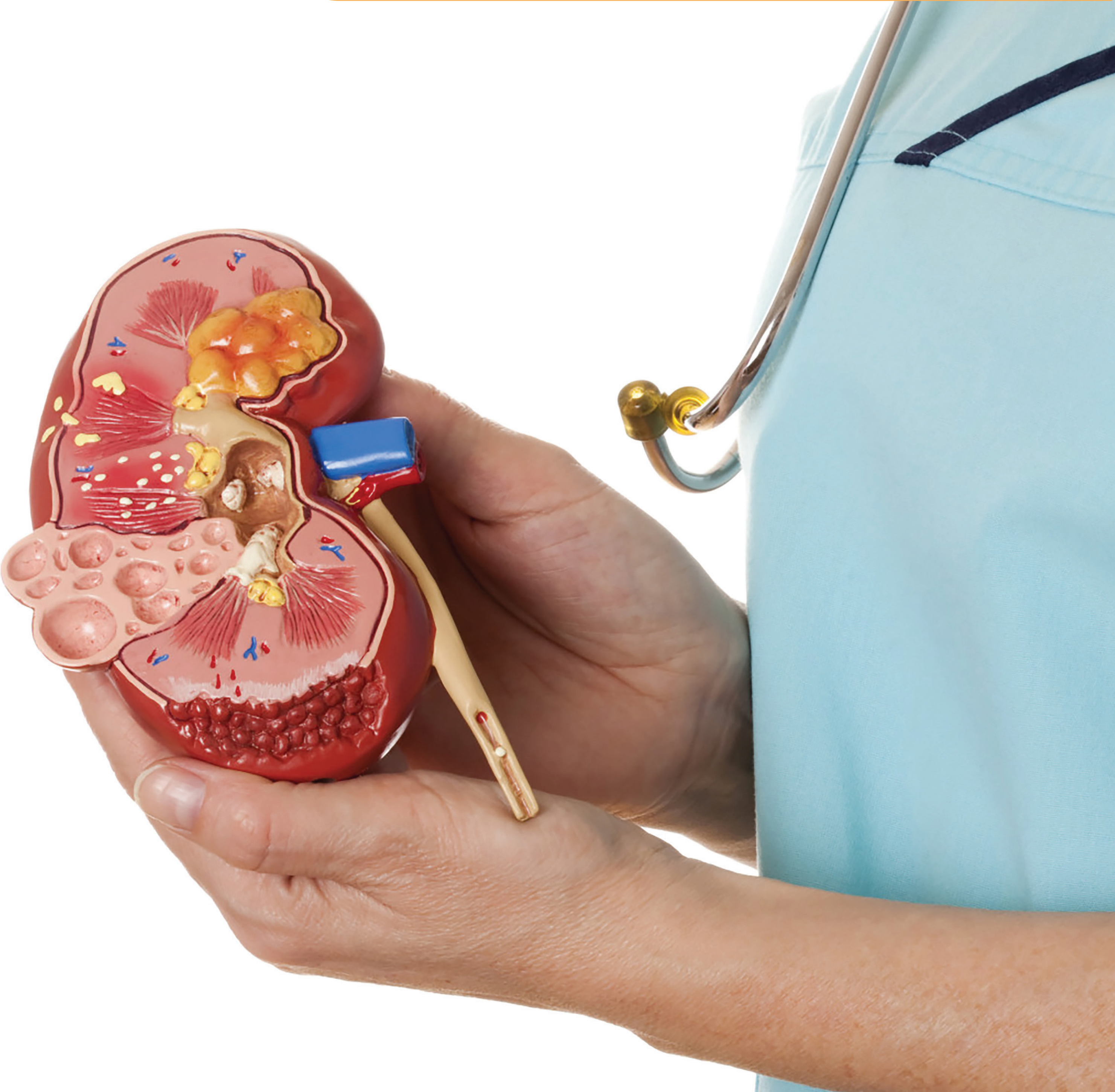
THE KIDNEY CITIZEN

A publication of Dialysis Patient Citizens (DPC) Education Center



DPC EDUCATION CENTER



PRESIDENT'S MESSAGE

I often tell people "when you know better, you do better." That sentiment, is what drove a group of kidney failure patients (including me) a couple of years ago to create the Dialysis Patient Citizens (DPC) Education Center. We wanted to ensure that others delay and potentially avoid kidney failure, while also working to improve the quality of life for kidney failure patients (whether on dialysis or with a transplant) by empowering everyone through education. To maximize our impact, we formed our organization as an affiliate of Dialysis Patient Citizens, which will allow us to leverage its nearly 30,000 members. That said, we need your help to get this critical information out to individuals in your community, including your friends and family, and we want to make certain that you are successful in helping to spread the word.

First, to ensure that you have the resources you need to empower others, I am pleased to announce the introduction of our new print newsletter, entitled the "Kidney Citizen." We want to make sure that our educational resources are available to everyone. So, while we continue to develop new electronic communications, on-line resources and interactive learning opportunities, we are excited about the information included in the enclosed publication. Please share the stories that you read here with your loved ones. We also welcome your feedback and comments to help us make the Kidney Citizen even better in the future.

Second, we recently formed a new Advisory Council (see list on this page), with leaders from the kidney community and beyond. We are fortunate to have such a distinguished and diverse group of individuals reviewing and in many cases drafting the educational resources that you receive from us. I would like to personally express my appreciation to each and every one of these individuals, who are giving so generously of their time and expertise to help us advance our mission.

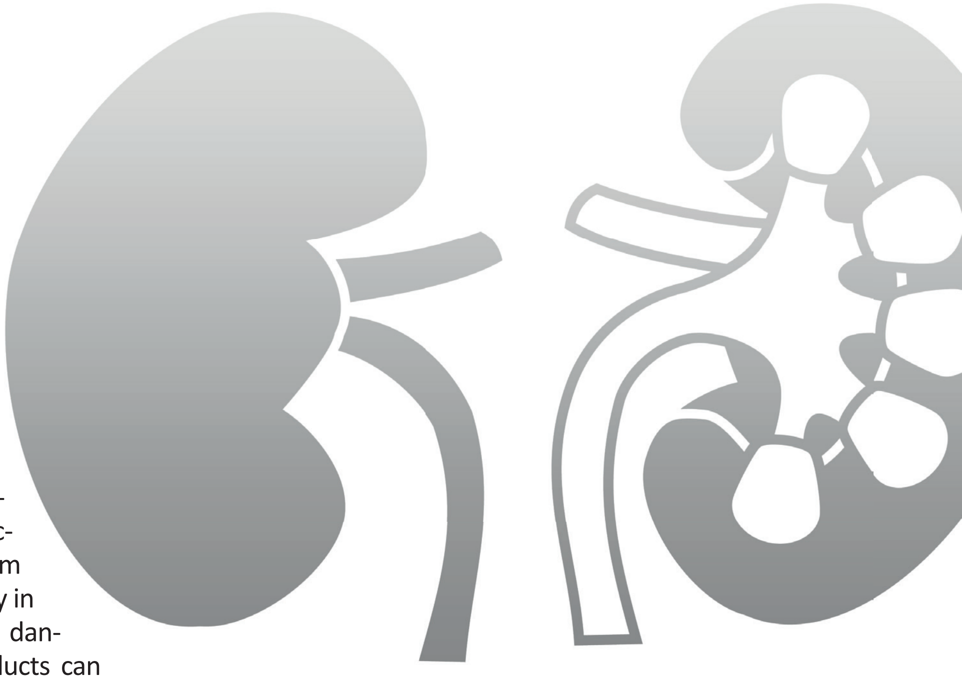
Finally, I want to encourage you to participate in our upcoming patient education webinars/ conference calls, and to ask that you invite others to join as well. We continue to recruit outstanding health care professionals as speakers for these events. Every month these experts discuss topics important to kidney disease patients in a way that is both informative and easy to follow. Our presenters also provide ample time to answer questions from our patient participants.

Only through education can we empower people to make the right decisions regarding their health. But, we need your help to let others know about our efforts, and to share the resources that are presented to you in this newsletter. I hope I can count on your support, as we work together to improve the quality of life for all kidney disease patients.

Sincerely,

Nancy L. Scott
Nancy Scott
DPC Education Center, Board President

Basics of Chronic Kidney Disease



Chronic kidney disease (CKD), also called chronic kidney failure, describes the gradual loss of kidney function. Your kidneys filter wastes and excess fluids from your blood, which are then removed from your body in your urine. When CKD reaches an advanced stage, dangerous levels of fluid, electrolytes and waste products can build up in your body and cause you harm.

In the early stages of CKD, you may have few signs or symptoms, and may only be diagnosed with a blood and/or urine test. In fact, you may not feel sick from CKD up until most of your kidney function is lost.

Treatment for CKD focuses on preventing more kidney damage and slowing the loss of kidney function by controlling the underlying cause and treatment of high blood pressure. CKD can progress to end-stage renal disease (ESRD), or total kidney failure. ESRD is eventually fatal without replacing the kidney function with treatments such as artificial filtering (dialysis) or a kidney transplant.

Signs and symptoms of kidney disease may include:

- Nausea
- Vomiting
- Loss of appetite
- Fatigue and weakness
- Sleep problems
- Changes in urine
- Decreased mental sharpness or confusion
- Muscle twitches and cramps
- Hiccups
- Swelling of feet, ankles, hands or face
- Persistent itching
- High blood pressure (hypertension) that's difficult to control
- Chest pain, due to fluid building up around the lining of the heart
- Shortness of breath, because of fluid building up in the lungs

Signs and symptoms of kidney disease are often nonspecific and may be caused by other illnesses. Also, because your kidneys are highly adaptable and able to compensate for lost function, signs and symptoms may not appear until irreversible kidney damage has occurred. Make an appointment with your doctor if you have any signs or symptoms of kidney disease or are told that your blood or urine tests raise concern for CKD.

Diseases and conditions that commonly cause CKD include:

- Type 1 or Type 2 diabetes
- High blood pressure (hypertension)
- Glomerulonephritis (gloe-mer-u-lo-nuh-FRY-tis), damage of the kidney's glomeruli, or filtering units), including from conditions such as lupus
- Interstitial nephritis, damage of the kidney's tubules, or pipes, and surrounding structures
- Polycystic kidney disease
- Obstruction, or blockage of the urinary tract, from conditions such as enlarged prostate, kidney stones and some cancers
- Vesicoureteral (ves-ih-koe-yoo-REE-ter-ul) reflux, a condition that causes urine to back up into your kidneys
- Recurrent kidney infection, also called pyelonephritis (pie-uh-lo-ne-fry-tis).
- Factors that may increase your risk of CKD include:
- Heart disease
- Smoking
- Obesity

- High cholesterol
- Being African American, Native American or Asian American
- Family history of kidney disease
- Being age 65 or older

If you have a medical condition that increases your risk of CKD, your doctor may check your blood pressure and kidney function with urine and blood tests during regular office visits. Ask your doctor if these tests are recommended for you.

CKD can affect almost every part of your body. Potential complications include:

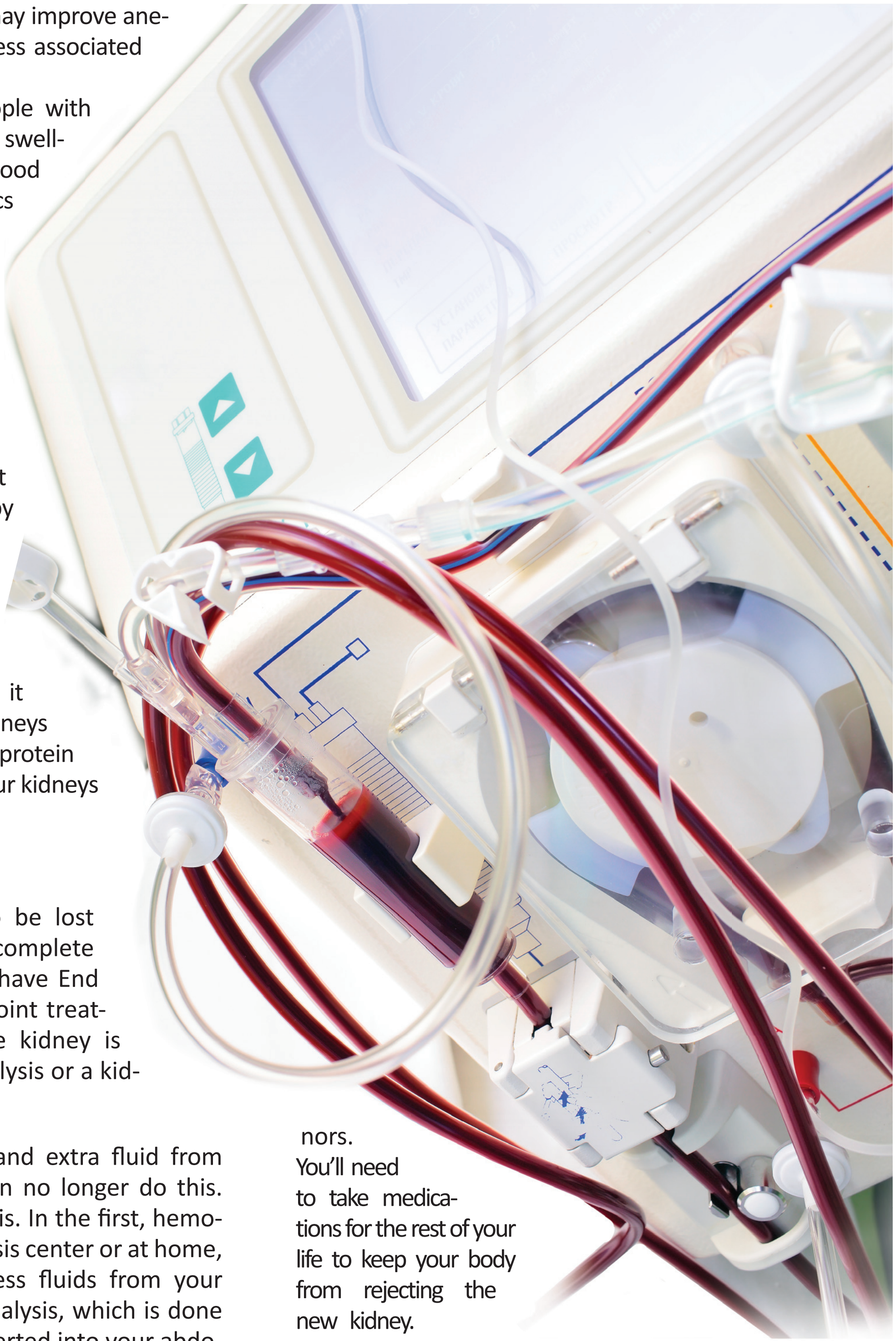
- Fluid retention, which could lead to swelling in your arms, legs, or face, high blood pressure or fluid in your lungs (pulmonary edema)
- A sudden rise in potassium levels in your blood (hyperkalemia), which could impair your heart's ability to function and may be life threatening
- Heart and blood vessel disease (cardiovascular disease)
- Weak bones and an increased risk of bone fracture
- Anemia
- Decreased sex drive or impotence
- Damage to your central nervous system, which can cause difficulty concentrating, personality changes or seizures
- Decreased immune system, which may increase your risk of infection
- Pericarditis, an inflammation of the lining (pericardium) that surround your heart
- Pregnancy complications for the mother and the developing fetus
- Irreversible damage to your kidneys (end-stage kidney disease), eventually requiring either dialysis or a kidney transplant for survival.

Depending on the underlying cause, some types of kidney disease can be treated to avoid developing total kidney failure. This may include controlling other chronic conditions such as diabetes or high blood pressure. However, chronic kidney disease often has no cure. In general, treatment goals are to control signs and symptoms, reduce complications, and slow the loss of kidney function.

Treating complications

Kidney disease complications can be treated to make you more comfortable. Treatments may include:

- Medications to control blood pressure. People with kidney disease may experience high blood pressure. Your doctor may recommend medications to lower your blood pressure. A common type of medication recommended is angiotensin-converting enzyme (ACE) inhibitors or angiotensin II receptor blockers. Research studies have shown that these medications prevent the loss of kidney function. High blood pressure medications can decrease kidney function and change electrolyte levels in your blood, so you may need frequent blood tests to check on how your body responds to these medications. Your doctor may also recommend a water pill (diuretic) to remove extra fluid and a low-salt diet.
- Medications to lower cholesterol levels. Your doctor may recommend medications called statins to lower your cholesterol. People with CKD often experience high levels of bad cholesterol, which can increase the risk of heart disease.
- Medications to treat anemia. In certain situations, your doctor may recommend supplements of the hormone erythropoietin (uh-rith-roe-POI-uh-tin). Your doctor may also recommend iron. Erythropoietin helps the body to



make more red blood cells, which may improve anemia and relieve fatigue and weakness associated with anemia.

- Medications to treat swelling. People with CKD may retain fluid. This can lead to swelling in the legs, and worsen high blood pressure. Medications called diuretics can help remove fluids from your body.
- Medications to protect your bones. Your doctor may recommend calcium and vitamin D supplements to prevent weak bones and lower your risk of fracture. You may also take medication to lower the amount of phosphate in your blood, to protect your blood vessels from damage by calcium deposits (calcification).
- A lower protein diet. Your doctor or dietitian may recommend a lower protein diet to minimize waste products in your blood. As your body digests protein from foods, it creates waste products that your kidneys must filter from your blood. A lower protein diet reduces the amount of work your kidneys must do.

Treatment for ESRD

If your kidney function continues to be lost despite treatment, and you develop complete or near-complete kidney failure, you have End Stage Renal Disease (ESRD). At that point treatment to replace the function of the kidney is needed. Two options are available: dialysis or a kidney transplant.

- Dialysis. Dialysis waste products and extra fluid from your blood when your kidneys can no longer do this. There are two main types of dialysis. In the first, hemodialysis, which can be done in dialysis center or at home, a machine filters waste and excess fluids from your blood. In the second, peritoneal dialysis, which is done at home, a thin tube (catheter) inserted into your abdomen fills your abdominal cavity with a dialysis solution that absorbs waste and excess fluids. After a period of time, the dialysis solution drains from your body, removing the waste with it.
- Kidney transplant. A kidney transplant involves surgically placing a healthy kidney from a donor into your body. Transplanted kidneys can come from deceased or living donors. You'll need to take medications for the rest of your life to keep your body from rejecting the new kidney.

For some who choose not to have dialysis or a kidney transplant, a third option is to treat your kidney failure with conservative measures. This includes working closely with your doctor and maybe palliative care specialists to ease your symptoms and any complications. However, once you have complete kidney failure and you make little or no urine, most people cannot survive more than a few weeks.

What is advance care planning and why is it important for dialysis patients?

By | Dr. Prayus Tailor, Nephrology Associates

I am a nephrologist. About five years ago, my father had a sudden cardiac arrest in front of me. I was able to quickly initiate CPR. By the time the ambulance arrived, he had regained consciousness. He lived for another two years, but unfortunately became critically ill after developing leukemia. An infection had overtaken his body. He was then in the intensive care unit (ICU) on multiple antibiotics and drugs to treat the infection and keep his blood pressure up so that his organs could continue to get blood flow. His kidneys started failing quickly. I remember the ICU team calling me and telling me he was not doing well. We gathered the family and went to his hospital room. Upon speaking with the intensive care unit doctor and nephrologist, my family and I were left with the difficult decision of whether to start dialysis. As a physician, I knew his prognosis was not good. As a nephrologist, I knew dialysis would not fix what was killing my father. And yet, even with this background knowledge, I hesitated to answer when the nephrologist asked me whether my father, who could no longer answer for himself, would want to proceed with dialysis. His condition was deteriorating quickly. I instructed the ICU team not to perform any life saving measures and allow him to pass away naturally. He died within minutes.

When I think back to my father's last days and moments with us, I ask myself, "Why didn't we talk to Dad more about what he would want if he could not tell us for himself?" He had had two cardiac bypass surgeries in the past, but we never talked about it. I actually tried to start a conversation with him about his care goals after his cardiac arrest, but he didn't want to talk about it. He never made a will or outlined his goals of care. I don't think he wanted to think about his own death. As a doctor, I felt somewhat ashamed that we did not talk about these important issues. As a son, it was not a conversation I wanted to have. I can't tell you why I didn't push harder to have these conversations. I knew it would just be very uncomfortable. I did not want to push the conversation if he did not want to have it. But, I know that the anguish my family members and I went through in terms of how aggressive to be with his care would have been lessened if my father had talked to us about what he wanted for his goals of care.

Advance care planning, as described by the Renal Physicians Association's Guideline on Shared Decision Making, is a process wherein the patient (or his healthcare power of attorney or healthcare proxy) and the physician hold a discussion to:

a. help the patient understand his/her condition
b. identify his/her goals of care
c. prepare for the decisions that may have to be made as the condition progresses over time

These are not easy conversations to have, but many dialysis patients feel better knowing that they have had this discussion with their family, physician and/or social worker. By engaging in advance care planning, patients are able to maintain their autonomy and sense of control over their future. Patients have some peace of mind knowing that they have lifted the burden of family members having to make difficult healthcare decisions on their behalf.

There are different ways in which a patient can make his wishes for future healthcare known. Some examples are outlining the wishes in the form of an advanced healthcare directive, designating a healthcare power of attorney or by completing a Medical Order for Life-Sustaining Treatment (MOLST) form. Most states in America have some type of MOLST or similar form that can be filled out by the doctor and patient and be kept on record so that the patient's wishes can be reviewed if and when they are not able to communicate this information to the healthcare team. The MOLST is a portable and enduring medical order form covering options for cardiopulmonary resuscitation (CPR) and other life-sustaining treatments. These orders are based on the patient's wishes about future medical treatments. Having a MOLST form will increase the likelihood that the patient's wishes regarding life-sustaining treatments are adhered to across the continuum of healthcare. For example, the orders would carry over from the dialysis unit to the hospital and vice versa.

Looking back at my experience with my father's death, I can say that the decision process would have been less difficult had my father had these discussions with us and his doctors well ahead of time. Dialysis patients should take the opportunity to talk to doctors about expectations for life span and quality of life, and speak to family about what they would and would not want done if they are no longer able to decide for themselves.

More information on advanced directives for dialysis patients can be found online at the Coalition for Supportive Care of the Kidney Patient's website (www.kidneysupportivecare.org).

Oregon Program with Kidney Focus Empowers Youth

By | Dr. Cheryl Neal, Founder of MIKE

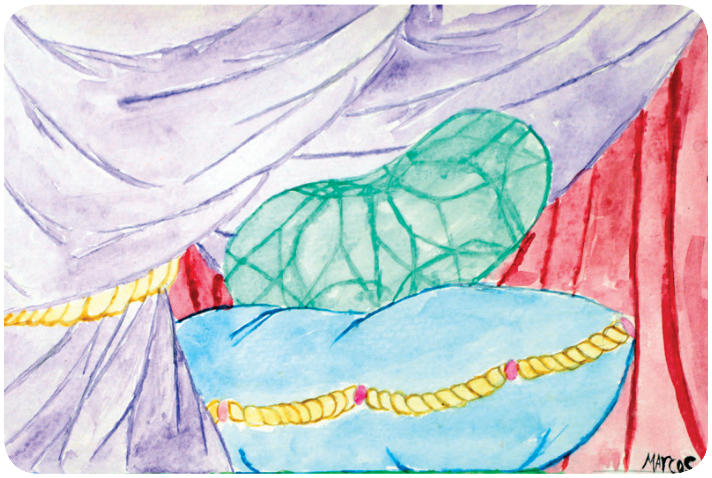
Inside David Mickola's health class at De La Salle North Catholic High School in Portland, Oregon, excitement is building. Teams of ninth graders are busy creating replicas of kidneys from basic household items. The activity is part of the Multicultural Integrated Kidney Education Program's (MIKE) health science education programming for underserved youth at a variety of schools in the region. The team which demonstrates a filtering system that best matches the filtering process of the kidneys will earn extra points.

MIKE is a nonprofit charity in Portland founded by Dr. Cheryl Neal, the widow of Dr. Michael Hartnett, a nephrologist who passed away in 2000. Dr. Neal, who practiced internal medicine, along with some of Dr. Hartnett's colleagues and friends, came together during his memorial service to recognize Hartnett's contributions to the community. Together, these volunteers soon began a legacy of mentoring diverse teens toward healthy behaviors that has now reached more than 1100 young people throughout the Portland region.

Back inside Mr. Mickola's classroom, each group of teens works with a near-age mentor who serves as a guide and positive role model. MIKE recruits, trains and places caring mentors with the youth in their schools once a week. Most of MIKE's mentors are health professions students who volunteer their time for at least one semester to guide youth toward healthier lifestyles. The mentors, in turn, experience health delivery in blended cultural, ethnic and low socio-economic communities.

MIKE staff and mentors support youth through hands-on activities like the "build-a-kidney" activity in a comprehensive health science program once a week. In fact, many of the hands-on activities in MIKE have been inspired by youth participating in MIKE.

The “build-a-kidney” activity was first introduced by a group of MIKE teens as part of their health leadership project. MIKE’s health leadership projects are designed with a community-service intent. By sharing their message with others, the youth develop confidence to advocate for others. Each team chooses how and where they present their projects. Many like to focus on their younger peers at local grade and middle schools. Other MIKE teams have created videos, musical and performance pieces and hosted a variety of health fairs.



For the youth, MIKE is as much about building positive relationships and life skills as it is about health. Most of the youth complete the program amazed that learning about health could be so much fun. Each week, MIKE mentors bring healthy snacks and water to class to encourage healthy habits. The youth learn about nutrition, physical activity and chronic disease prevention. Midway through the program, the youth take part in a healthy food scavenger hunt at a local grocery store to test their skills.

One of the most compelling experiences for youth in MIKE is a visit to a local dialysis clinic. Yasuyo Tsunemine, a Fresenius Medical Care social worker at the Scholls Ferry Dialysis Center, has hosted dozens of visits. Tsunemine and other staff at several Fresenius centers introduce MIKE youth to a variety of health career options, show how a dialysis center operates, and most importantly, encourage the teens to speak with some of the patients.

“I learned what’s it’s like to be a dialysis patient,” said Selah. “I like that we got to see the real thing and talk with patients,” said Florinda. Daniel said the visit, “Helped me learn that life is precious.”

Before the visits, MIKE staff and mentors prepare the youth by helping them understand chronic diseases and the conditions leading to kidney failure. “One thing that shocked me the most was when the nurse told me that the number one cause of kidney failure was diabetes,” said Dion, one of MIKE’s afterschool program participants at Liberty High School in Hillsboro, Oregon. Liz added, “It was a big eye-opener. It showed me how lucky we are.”

The purpose of the visits is best reflected by the youth, like Manny who stated, “It was worthwhile because it made me realize I need to be healthier and take care of my body.” Columbia added, “I learned you have to take care of your kidneys.”

For more information about MIKE, visit www.mikeprogram.org.

How do kidneys help to keep bones healthy?

By | Ana Edjlali, RD

Keeping your bones healthy is an essential goal when dealing with kidney disease. Your kidneys play an important role in maintaining a healthy bone structure. They do this in three ways:

***Activating vitamin D*:** Healthy kidneys help the body absorb calcium and turn the Vitamin D that our skin absorbs from sunlight into a form of Vitamin D the body needs to keep bones strong and healthy. When kidneys are not working, they no longer activate vitamin D and calcium is not absorbed well. This leads to a type of bone disease called CKD-MBD, causing your bones to get brittle and weak over time.

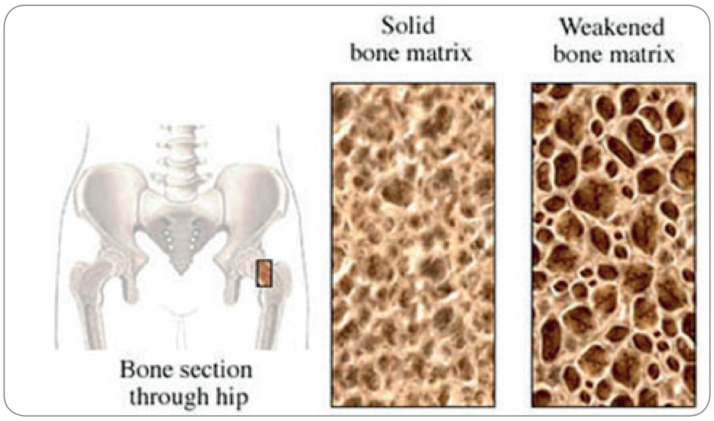
Balancing phosphorous: Healthy kidneys also control the level of phosphorous in your blood by removing extra phosphorous. In chronic kidney disease (CKD), phosphorous builds up in your blood and can reach toxic levels. High phosphorus levels cause the body to pull calcium out of your bones, making bones weak and more prone to injury. High blood levels of calcium and phosphorus can result in formation of bone like tissue (calcification) in tissues such as blood vessels, lungs, eyes, skin and heart, leading to cardiovascular disease or even death. Phosphorus and calcium control is very important for your overall health.

***Working with parathyroid glands**:* Your kidneys work closely with four small glands called parathyroid glands, located in your neck near your thyroid gland. These glands work to keep a normal level of calcium and phosphorous in the blood. When kidneys fail, the body experiences many changes that phosphorous levels may get higher than normal. High phosphorous levels stimulate parathyroid glands to release a hormone called parathyroid hormone (PTH). In response, PTH pulls more calcium and phosphorous from bone. This makes the bone disease worse, and makes you much more prone to fractures.

How do you know if you have bone disease?

Bone disease can start developing without any symptoms even before a patient begins dialysis. Therefore, it is very important to diagnose it early and prevent or slow down its progress. Your doctor can check how healthy your bones are by:

- Running a blood test to check the levels of:
- Calcium
- Phosphorous
- Parathyroid hormone (PTH)
- Vitamin D
- Sometimes it may be necessary for you to get biopsy from your bone Bone density X-ray (DEXA)



Solid bone vs. weakened bone. http://www.bidmc.org

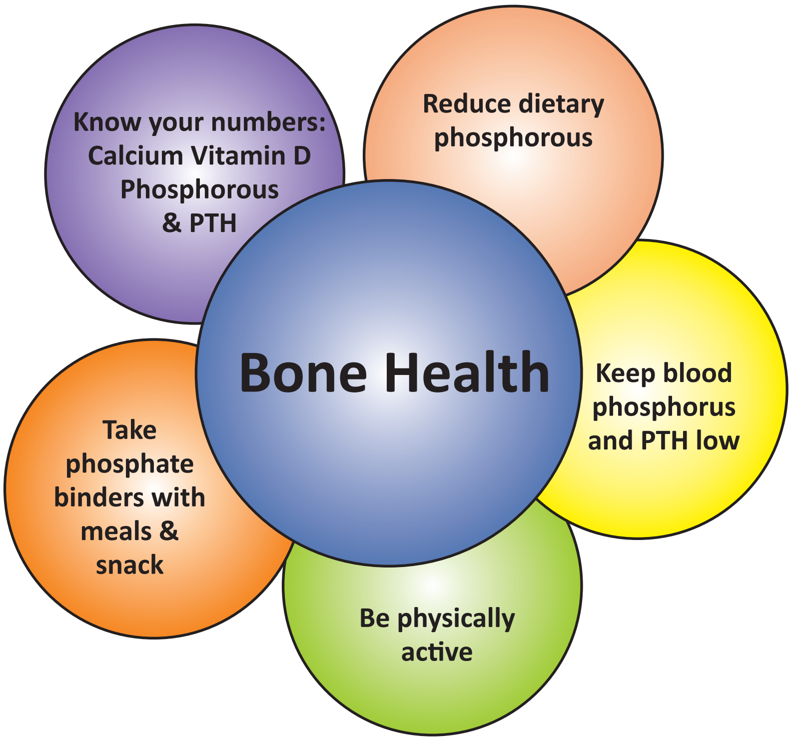
Common signs and symptoms of renal osteodystrophy bone disease include:

- High phosphorous and PTH levels
- Low calcium and vitamin D levels
- Bone and joint pain
- Bone deformation or fractures
- Poor mobility

Talk to your doctor if you experience any of these signs or symptoms.

What can you do to help prevent or slow down bone disease?

Remember, despite the challenges of kidney disease, you have the power to lead a healthy life. With attention to your



diet, medications, and some physical activity in your daily routine, you can help your body reduce and repair any bone damage associated with kidney disease. The following gives you tips to prevent or slow bone disease:

Keep your blood calcium and vitamin D levels in check:

Get your calcium and vitamin D levels checked regularly, along with other labs. If your blood calcium is too low, your doctor may prescribe a calcium & vitamin D supplement to raise your blood levels. ** Any dietary supplements must be prescribed ONLY BY YOUR PHYSICIAN.* AVOID taking any over-the-counter supplements.

Maintain a low blood phosphorous level:

Reduce your dietary sources of phosphorous to lower phosphorous levels. Phosphorous is especially high in dairy, dried beans, peas, nuts, and soft drinks. Talk to a dietitian to know what foods you can choose with lower phosphorous.

Take your phosphate binders with each meal and snacks.

Be physically active:

- *Exercise may not be safe for you if your medical condition is not stable. So, always check with your doctor first.
- A simple 15-30 minute walk each day can strengthen your muscles, bones, and improve your emotional health. If you feel you can't commit to 30 minutes of exercise at one time, break it down into three ten minutes throughout the day.
- Start with small steps such as a 10 minute walk, gardening, or dance. Build it up gradually. Choose activities that give you joy. Remember, any activity is good.

> *Life can turn out much better than you think. So, never lose hope.*

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Receiving Adequate Iron is Essential for My Good Health

Today, there is a product that can deliver iron consistently at every dialysis treatment in place of IV iron… it's called Triferic.

Hemodialysis patients lose iron with each dialysis treatment due to the consistent blood loss that occurs. Patients lose approximately 5 -7 milligrams of iron every hemodialysis treatment. Therefore, iron is needed every dialysis treatment, to replace the ongoing iron loss that occurs during hemodialysis.

Triferic is the only FDA approved drug indicated for iron maintenance therapy.

Triferic is delivered via dialysate, simply replacing the 5-7 milligrams of iron lost during your regularly scheduled dialysis treatment. Triferic enters your blood and immediately binds to transferrin (the natural carrier of iron in the body) and is taken to the bone marrow, bypassing the liver, similar to normal dietary iron uptake. Your body will use the iron to make hemoglobin. Hemoglobin will carry oxygen throughout your body, providing energy.

Triferic is the only drug FDA approved to replace iron at every hemodialysis treatment and to maintain hemoglobin concentration.

- Iron delivered at every dialysis treatment
- Replaces the 5-7 milligrams of iron that is needed
- Maintains hemoglobin concentration
- Does not increase iron stores and inflammation (ferritin)

Triferic does not require intravenous infusion. There are no IV's or needles required to receive Triferic. Triferic is simply mixed into your dialysate and administered to you throughout the hemodialysis procedure.

The safety profile of Triferic has been demonstrated in long-term studies and is similar to patients receiving placebo treatment. There have been no severe life threatening hypersensitivity reactions in over 100,000 doses administered.

For more information, ask your doctor about Triferic or call Rockwell Medical at 800-449-3353.

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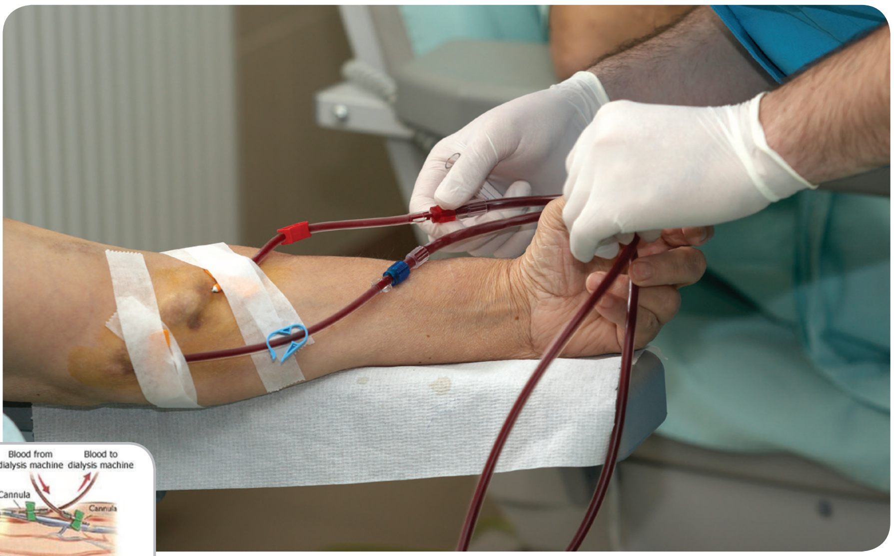
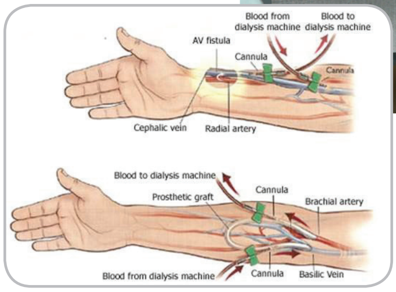
Hemodialysis Access for Patients

(The Care and Feeding of Your Dialysis Access)

By | Dr. Steve Curtiss,



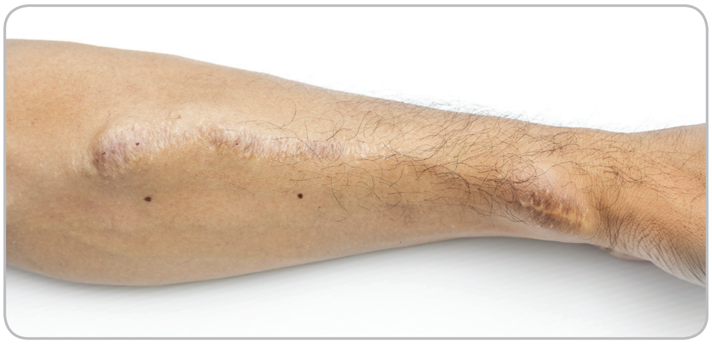
Problems with dialysis access are a leading cause of complications and hospitalizations of patients with kidney disease. The more patients understand about their access, the more they are empowered and can become an important part of the healthcare team, which leads to an improved quality of life by staying out of the hospital and having efficient dialysis. It is also important for patients not yet on dialysis to understand the types of dialysis access available so they can be prepared and make informed choices about dialysis access when they are not in crisis. This also helps to prevent starting on dialysis with a catheter as an emergency procedure.



An Arteriovenous fistula (AV) is the preferred type of access. A superficial vein in the arm is sewn to an artery and the vein enlarges over period of about six weeks until the patient can be attached to the dialysis machine by placing needles in the vein. This is the best type of access in terms of working the longest and having the least complications. Unfortunately not everyone's veins are good enough to have an AV fistula. Some patients will have an AV graft where a special Teflon tube is used as a bridge between an artery and vein under the skin. This can be used for dialysis in about two to three weeks or less, but may not continue working as long as a fistula. Sometimes a patient requires a catheter to be placed in one of the large veins in the neck if dialysis is needed more urgently. This type of access is associated with a high rate of infections and should be avoided unless absolutely necessary.

There are several steps a patient can take to insure a well-functioning dialysis access and prevent complications and hospitalization. They are important for both patients on dialysis and those that have not yet started dialysis:

The key to a successful access is giving the surgeon good veins to work with. It is essential that any patient being considered for dialysis only have blood draws and IVs in one arm and save the other arm for an access. You want to save your non-dominant arm (the one you do not use for eating and writing to use for a vascular access.



The patient should feel the access every day and, if possible, listen with a stethoscope to make sure the blood is still flowing through the vein. They need to be aware of signs of a poorly functioning access such as prolonged bleeding from needle holes, arm swelling, cannulation difficulties (trouble putting the needles in) or inability to complete a treatment. Any concerns should be brought to the attention of their dialysis providers immediately.

Sores and ulcerations or scabs over an access can lead to infection and/or excessive bleeding. The access surgeon or nephrologist should be notified immediately.

Access maintenance is an ongoing process. The relationship with your access surgeon is a long term relationship and begins not ends with the creation of the access.

Why DPC Supports Opening Medicare Advantage Enrollment to Dialysis Patients

By | Jackson Williams, Government Affairs Director for Dialysis Patient Citizens

Would dialysis patients benefit from being allowed to enroll in Medicare managed care plans? Many health policy experts in Washington D.C. admire the leading integrated insurer/delivery systems such as Kaiser Permanente and Group Health Cooperative, and view them as models for transforming traditional Medicare. But outside of certain regions of the U.S., most American consumers remain skeptical of private health insurers. Managed care requires trading off retaining your choice of providers that traditional Medicare gives beneficiaries against a chance to receive other benefits.

DPC does not advocate that ESRD patients should abandon traditional Medicare to enroll in a managed care plan. But we do favor patients having the maximum choice among coverage options, to be exercised in consultation with counselors in their state health insurance assistance programs. Choices should include staying in employer group health insurance, access to exchange health plans under the Affordable Care Act, the ability to buy Medigap supplemental insurance, and the ability to enroll in Medicare Advantage plans. Below we review the pros and cons of Medicare Advantage plans.

Pro: Medicare Advantage plans have greater flexibility to coordinate care than traditional fee-for-service (FFS) Medicare.

The Medicare Payment Advisory Commission (MedPAC) has noted that "private plans, because they are paid a capitated rate rather than on a fee-for-service (FFS) basis, have greater incentives to innovate and use care management techniques." Capitation means that a health plan is paid a flat fee (about $88,000 per year) to care for a dialysis patient. In contrast, in FFS Medicare, each provider is paid under separate "silos": Medicare Part A for dialysis and hospitals, Part B for physicians, and Part D for prescription drugs. FFS Medicare payment rules are very prescriptive; for instance, Part D cannot pay for vitamins even if a nephrologist prescribes them, and Part B can't pay for transportation to a dialysis facility unless a patient needs an ambulance. A Medicare Advantage plan must provide all the benefits of Traditional Medicare, but it may also pay for additional services if it thinks those will preserve the enrollee's health and save money in the long run. For example, the CareMore health plan assigns a nurse practitioner to each ESRD patient in addition to the nephrologist, and provides transportation if necessary to prevent missed dialysis sessions. This has reduced ESRD patients' hospital admissions by 36% and inpatient hospital days by 62%.

Pro: ESRD patients could benefit from Medicare Advantage's out-of-pocket limits

Part C has historically been favored by lower-income beneficiaries who cannot afford Medigap supplemental insurance. Since Medigap is not universally available to ESRD patients under 65, Part C could be an opportunity for ESRD patients to limit their out-of-pocket costs. MA plans have maximum out-of-pocket limits of $6,700, and most plans limit cost-sharing to $5,000 or less. But dialysis patients, restricted to fee-for-service Medicare, on average face cost-sharing of at least $15,000. Moreover, MedPAC found that three-fourths of enrollees who selected plans before their kidneys failed and remained in those plans afterward are in plans that charge no co-payment or coinsurance for dialysis.

Con: Managed care plans require referrals for specialty care and limit coverage to in-network providers.

Unlike fee-for-service Medicare, which permits beneficiaries to see any Medicare participating provider without prior authorization, Medicare Advantage plans have networks of physicians, hospitals, dialysis facilities and transplant centers. Sometimes patients receive contradictory information from health plans or become confused about the circumstances in which they can see a provider, leading to coverage denials and a complicated appeals process. The Medicare Rights Center reports that 30% of the calls to its national helpline involve how to manage coverage denials and appeals.

Remember, if Congress permits ESRD patients to enroll in Medicare Advantage, you as the patient will make the decision on your enrollment. If you are satisfied with the care arrangements you currently have through original Medicare, you would be able to keep them.

The Gift of Life-- A Donor's Perspective

By | Joanne Smith, Education Manager, DPC Education Center

On August 11, 2015, I had the wonderful opportunity to provide a fellow human being with a kidney.

Growing-up my grandfather told me "giving is a wonderful thing and it makes you feel real good." He made me realize that when someone is giving something to you, they have the same opportunity to feel "real good." I learned to be a generous giver, but more importantly to be a gracious receiver. This actually enables others to enjoy the feeling of being generous givers as well. So, please don't be afraid to ask your friends and family members to become kidney donors for you.

I began my journey to kidney donation several years ago, when a family tragedy led me to the nursing profession. It actually led me back to school at the age of 32, where I attended college to earn my RN degree. Shortly, thereafter I began to work for a privately owned dialysis facility serving in-center dialysis patients.

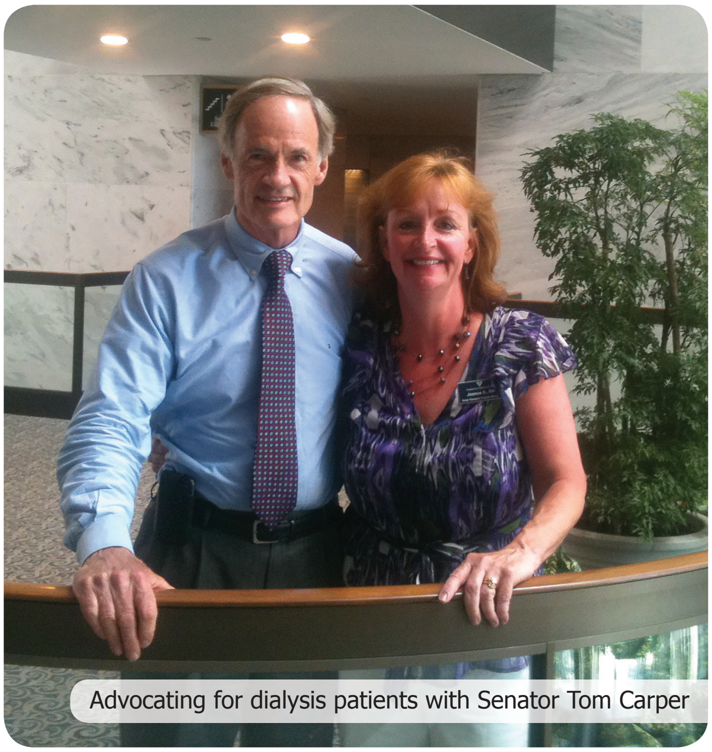
After one year, the attending nephrologists bought their own facility and I left to be their Director of Nursing. I loved that in dialysis you could provide quality continuity of care, because the patients came three times each week. My patients quickly became like family members.

Within the next year, our clinic was bought by one of the big dialysis companies. I worked acute dialysis, dialysis cruises and in-center dialysis for another 12 years.

Then the opportunity was presented to me to learn about home dialysis. Initially, I thought that it may be too difficult for anyone to do home dialysis. I was wrong. Home dialysis gives patients the opportunity to receive treatment five to seven times a week which is how the body is programmed to have toxins and excess fluid removed and all other chemistries balanced. Since then, I have been overseeing several home dialysis clinics with over 150 patients performing their treatments at home, staying healthier and happier and in control of their lives.

As a dialysis nurse, I also teach options classes about kidney disease. These classes inform CKD patients about the common causes, the progression of kidney disease and what options are available. That donors we can live without the

Education Manager Joanne Smith



Advocating for dialysis patients with Senator Tom Carper

need for renal replacement therapy with only 25% of one kidney functioning. And, as a chronic kidney disease educator I encourage families and friends who attend the Treatment Options programs to consider donating a kidney, "after all, that's why God gave us two."

Over the years, I have talked to countless family members and friends about donating a kidney, but I never felt it was the right time for me. I felt comfortable in the knowledge that before a donation, every possible type of testing is performed including psychological to make certain that once that kidney was donated, the donor's chances of having kidney failure would be minimal. In fact, the statistics state that donors actually have less chance of having kidney failure than the general population. This has to do with the fact that a donor must be in good health in order to donate a kidney.

My initial interview with the transplant team happened in early May. I had been to my church the day before for services and God put the name of one of my patients in my mind and I wondered why I didn't think of him myself. It seemed like the perfect time to be able to donate.

My staff are a team of wonderful nurses, patient care techs, secretaries, social workers and dietitians that have the same values as me. They work together and independently to achieve quality goals for all of our patients. I had great faith in them that they would continue in my absence. I had plenty of vacation and sick leave built up, and family members available to assist me when I was discharged after surgery. I also had a discussion with my supervisor and medical director who were very supportive of my decision.

During May, June, and July, I had every imaginable type of testing from blood work for infectious diseases to stress tests, EKG, echocardiograms, and renal scans, you name it.

I met with the surgeon, nephrologist, social worker, dietitian, donor advocate and pharmacist for the transplant team several times. Each time, test results were reviewed as well as the plan for surgery. Every discussion contained the fact that no matter how far into the testing I went, I always had the right to change my mind and the team would support that decision. I knew everything that could happen. My mind was set.

Finally, the surgery was scheduled. My family and friends met with the recipient and his wife at my house for a celebration two days before the surgery. We were welcoming them into our family.

I had known my recipient for six years as he was a home-hemodialysis patient. In his early 40's he was diagnosed with cancer of the kidney and came to find out that he was only born with one kidney. That meant that after the cancerous kidney was removed, he would need dialysis immediately to sustain his life.

He started in-center dialysis and after he was educated on home dialysis, decided he would do peritoneal dialysis (PD). That is when we met.

PD went well for a while, but he had some complications such as hernias and infections and ended up having to change from PD to homehemodilaysis.

He was always optimistic and upbeat when he came to the clinic for his monthly visit. Several of his family members were tested for donation, but for one reason or another were unable to donate. I did not want to let him know that I was being worked up to donate until I was sure things would work out.

Finally the transplant team suggested that I let him know that I was being worked-up to donate a kidney to him...

I was excited, but felt awkward when I went to his house on a Saturday morning. I knocked on the door and could hear his wife running the vacuum. I knocked again, no answer. I happened to have his number in my phone from being on call, so I called and he answered. He was surprised that it was me and said "I didn't recognize the number and was hoping it was a call for a kidney." He called down to his wife to open the door as he was on his dialysis machine at the time.

We had met several times in the past. She was very supportive of her husband's disease and treatment and had accompanied him to the clinic for his monthly visits. I asked her to step outside for a minute and I told her I was getting worked up to donate a kidney to her husband. She looked shocked and then started to cry and hug me. She thanked me. I told her I had wanted to donate for years and that her husband's name came to me during my prayers in church. I then asked her if she would let her husband know, but she insisted that I tell him.

We went upstairs and he was sitting beside his bed attached to


Kidney donor and recipient.

the dialysis machine that was keeping him alive. He greeted me and again said that he didn't recognize the number and thought it might be a call for a kidney and laughed.

I started in with, "well, it was a call for a kidney," he looked puzzled and his wife said that I was there to tell him I was being worked-up to donate a kidney for him. He looked stunned. He started objecting saying, "what about you?" His wife interjected that I had wanted to donate a kidney for years and that I was donating to him or someone so he should definitely consider accepting. I excused myself saying I had to get back to my dogs.

I continued with my usual routine of working and scheduling tests around my work schedule. A week went by. My recipient called me and asked if we were still on? "Absolutely" was my reply. I knew in my heart that God brought me to this and He would bring me through this. My good friend and confidant, Nancy Scott told me this.

Every test result I received, I let him and his wife know the results (the transplant team cannot give the recipient any medical information about the donor nor the donor any medical information about the recipient due to HIPAA regulations).

Finally, all the testing was complete for both donor and recipient and the date was set for surgery. I informed my supervisor that I would be out of work for four to six weeks after surgery. I also informed my supervisor at Dialysis Patient Citizens (DPC) that I might be unavailable for a few weeks due to donation. Of course, my DPC team members were very supportive and proud.

The day before surgery I had a pre-op EKG, took a bowel – prep similar to what is used before a colonoscopy, had some lab work and met with the transplant team again. Once again, I was asked if I was certain of my decision to move ahead and informed me that I could cancel right up to the first incision. I had no doubts. I kept waiting to get nervous. The doctor even told me that I could have an anti-anxiety pill the morning of surgery if I wanted. I guess God was my anti-anxiety medication. I knew everything would go as expected and it did.

After the surgery, I had a pain pump that I could use as needed, which I did use for the first three days. The surgeon implanted a lidocaine pump on my incision site and I had NO PAIN at the incision, but I had some deeper tissue pain which the pain pump helped with. Really, just a feeling of not being able to get comfortable.

I had an open cut incision versus a laprascopic surgery. This was my decision. I felt that an open cut with a partial rib removal would be quicker and allow the surgeon easier access to my left kidney.

Second day post-surgery, I was out of bed. Slowly at first, but eventually up sitting in a chair, showering, and on the mend. I was dischargedonthefourthdayaftersurgery.

My recipient's creatinine level also plunged back to normal as a result of a living donor transplant. Maintaining this level will allow my recipient to remain off renal replacement therapy and hopefully allow him to live another 20 or more years. Time to meet his unborn grandchildren, time to spend with his wonderful wife and family, who were all so supportive during his time on dialysis. Time for him to make a difference in the lives of many people, especially those diagnosed with ESRD. He has vowed to continue to help educate people about dialysis and now transplant.

My labs were abnormal for the first couple of days, but by my tenth day post op, my labs were back to normal (my creatinine is 1.1 which is a little higher than normal), but I only have one kidney now. I have a list of medications that I need to avoid to protect my one functioning kidney. I have attached that list as well. I will follow-up with the transplant team one month from my surgery date and then periodically to make sure I am doing all I can to live a healthy life and protect my one kidney.

This has been a wonderful, blessed journey for me. I feel that the gift I was able to give filled my heart and soul. My recipient has expressed his appreciation over and over, which is a little uncomfortable for me. I love giving, but receiving has never been a talent that I've mastered. I am getting better at it.

If you have any questions about my experience or wish to consider living donation, please contact me at:

Jsmith@dialysispatients.org.

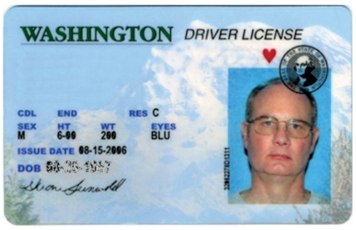
Can a Kidney Disease Chef Lose Weight?

By | Duane Sunwold

I'm a chronic kidney disease (CKD) patient that teaches in a culinary program. That means I'm around food ALL the time, plus the medication I was on caused me to gain an extra 70 pounds. I know managing your weight with kidney disease can be a challenge. Here are a few of the tips I used to help manage my weight.

Eating the right types of food was key to losing the weight. That meant I had to embrace my doctor's and dietitian's advice. I planned out my 3 meals and 3 snacks a day, and followed my dietitian's recommendations. Before I started eating, I would also portion out my food to control how much I was eating. On my good days, I would prepare meals in advance so when I was tired, I wouldn't cheat by eating fast food.

Before I changed my diet.



After I changed my diet

I also planned to use my good days to do some type of exercise. Always check with your medical team before starting an exercise routine. I would walk the dog, use the treadmill or even go swimming. I know my body does better if I keep it moving. For me, when I exercise, it decreases my aches and pains.

Fluid restrictions: ever hear of that? Yeah, I thought so. If I decreased the amount of salt I consumed, it was much easier to restrict my fluids. By preparing my own meals and reading food labels, I learned how much sodium was in a serving. I also learned not to use foods with hidden salt, like soy sauce, condiments, soup bases and canned soups; this helped me control how much water I drank.

Phosphorus is another mineral some kidney patients have to monitor. I only try to eat my phosphorus in naturally occurring foods, not foods that have been manufactured or drinks that contain phosphorus. I try to find low phosphorus foods to cook with. I braise cucumbers with dill, or cook apples with my vegetables in savory dishes.

Once I embraced my doctor's and dietitian's advice, I was able to start managing my weight. And I even felt better after 2 weeks.

Staying Well with Chronic Kidney Disease:

Basic Guidelines for Eating and Exercise

By | Danielle Kirkman, PhD

For some people with Chronic Kidney Disease (CKD), following a diet prescribed by their doctor may help to delay the need for dialysis.

A diet will not cure kidney disease.

A dietitian can help you develop a diet plan that follows your doctor's recommendations and is also realistic.

Eating healthy foods can help you feel well.

A meal plan made to fit your needs can help you: get to a healthy weight or stay at a healthy weight, control your blood pressure, control your blood glucose (sugar) and lower your risk of heart disease by giving you energy.

First, and most important, be sure to speak to your doctor or dietitian about your particular diet. Pay attention to fats. Include fiber. Limit sodium (salt). Learn how to include foods you enjoy.

There may be other nutritional changes that your doctor will prescribe. These changes may include the amount of protein, phosphorous and potassium you should eat. Your doctor or dietitian will help you learn how much of these foods are healthy for you to eat. Fat provides calories for energy. Healthier choices are mono-saturated and polyunsaturated fats, which include fish, olive oil, and canola oil. Too much fat can lead to weight gain. Too many saturated and trans-fats can increase cholesterol levels. Limit margarine, shortening, butter and animal fats.

Too much sodium (salt) can be harmful to your health. Limit the sodium in your diet to help control your blood pressure, control fluid buildup and swelling in your body and reduce your risk of heart disease and stroke. Avoid foods that are high in sodium. Some high sodium foods are table salt, canned foods, salty snacks, processed foods, processed deli meats, sauces, marinades, condiments and cheese. Your doctor will tell you the right amount of sodium to include in your meal plan.

Eat fresh or frozen foods when possible. Use low sodium flavorings, i.e. herbs and spices such as onions, lemon and garlic. Most vegetables are good sources of vitamins, minerals and fiber. It's good to include dark leafy vegetables and different colored vegetables. Talk with your doctor or dietitian to find out the amount of vegetables that are healthy for you.

Most fruits are good sources of vitamins, minerals and fiber too. A serving size is 1 medium size fruit or ½ cup fresh or canned fruit. Select a variety of fruits instead of fruit juice when possible to help manage your weight and blood sugar. Talk to your doctor or dietitian to find out the amount of fruit that is healthy for you.

Select low-fat or fat-free dairy foods. For people with kidney disease, dairy intake may need to be limited to lower phosphorus in your diet. Talk to your doctor or dietitian to find out the amount of dairy that is healthy for you.

Protein helps to build muscles and fight infections. People whose kidneys are not working well should avoid a high-protein meal plan. Protein is found in foods like meat, poultry, eggs and fish. Talk to your doctor or dietitian to find out the amount of protein that is healthy for you to eat.

Learn to read the labels on foods and know the serving sizes. Check the calorie count and look at the total fat, saturated fat and trans-fat. If your doctor or dietitian has recommended you to do so, look for the amounts of protein, carbohydrates, sodium, potassium and phosphorous in foods.

Know your goals and start with small changes. Keep a food journal and work with your doctor and/or dietitian. Ask your family and friends to help you. Know your lab values and talk to your doctor and/ or dietitian about your eating plan. Manage your weight and exercise (but ask your doctor first). Start slowly and engage in some activity every day - even a little bit will help. Get enough sleep and reduce stress. If you smoke, make a plan to stop. Don't forget to keep your doctor's, dietitian's and dentist's appointments and make sure you tell them about your kidney disease.

Kidney Disease

With Americans living longer and leading a more sedentary lifestyle, the incidence of chronic diseases continues to increase. Physical inactivity is a major risk for disease that remains one of the largest causes of premature death in the United States. Physical activity levels in chronic kidney disease (CKD) patients are markedly reduced and continue to decline as kidney function worsens. Low levels of physical activity in CKD patients are serious, as they are linked with poorer kidney function and they increase the already high risk of heart and blood vessel disease. A sedentary lifestyle also results in a loss of fitness and strength, thereby increasing the risk of disability and the loss of the ability to carry out your basic activities of everyday living. This starts a vicious cycle, as the weaker you become the harder it is for you to engage in physical activity and keep active.

It is therefore very important to keep active as a CKD patient. Over three decades of research has proven that dialysis patients can enjoy many health benefits through regular physical activity. First, taking part in regular physical activity helps to maintain your fitness and strength. Keeping up your strength will allow you to continue carrying out your activities of daily living unassisted as well as take part in leisure activities. As a result, you are more likely to remain independent and have a better quality of life.

Many factors of kidney disease make you more susceptible to heart and blood vessel disease. Increasing your physical activity level may reduce this risk. Regular exercise helps you manage your blood pressure. Research in both pre-dialysis and dialysis patients has shown that the amount of blood pressure medication was reduced following three to six months of regular exercise. Additionally, regular exercise makes your heart more efficient and improves the health and function of your blood vessels.

When the kidney fails, toxins and acids that are usually removed by the kidney build up in the blood. These toxins and acids, as well as the hemodialysis process, cause your muscles to degenerate and weaken. Not only do your muscles keep you strong and able to carry out everyday activities, but active muscles are important for a healthy metabolism, as they use up sugars and fat from the blood for energy. Increasing your physical activity keeps your muscles active and strong and prevents them from deteriorating.

In addition to the physical benefits, regular exercise has also exhibited many psychological benefits. Patients on hemodialysis have lower depression and anxiety levels as a result of increasing their physical activity levels. Regular physical activity helps reduce stress and leaves you feeling revitalized and relaxed.

Getting Ready To Increase Your Physical Activity

Safety first: Before you increase your physical activity or take part in any exercise consult your doctor. You should NOT exercise if:

- You have chest pains at rest or you have suffered a cardiac event in the last 6 weeks.
- You are breathless at rest and you have visible swelling from fluid overload
- You have an acute infection or a body temperature above 101°F
- You have poor diabetic control
- You do not take blood pressure medication and have a blood pressure above 160/100 mmHg

Set Your Goals: Set your main goal to increase your physical activity and share your goal with friends, family or your health care provider. By sharing your goals you create a support network to help you achieve your aims. Ensure that any goals you set are SMART: Specific, Measurable, Achievable, Realistic, and Time-based.

Split your main goal into smaller weekly realistic, achievable goals. For example:

Main Goal: "In six months' time I would like to be able to walk three miles per week."

Smaller Goals: "By next week I will make sure I have a comfortable pair of shoes to start walking to increase my physical activity levels"; "Over the next two weeks I will go for a 15 minute walk each day after my dialysis."

Identify Potential Barriers: Identify any barriers that may prevent you from achieving your goals in advance and make a plan to overcome these barriers. For example: "I will ask another dialysis patient who also wants to increase their physical activity to walk with me; that way when I don't feel like walking I will have someone to motivate me."

Increasing Your Physical Activity

If you currently take part in no physical activity, start at a low intensity and gradually increase the intensity and duration as you become stronger. Walking regularly is an easy, convenient way to increase your physical activity levels that has proven health benefits in CKD patients. Using a pedometer to count the number of steps you take per day is a good way to monitor your walking activity. Starting at a level that you are comfortable at, increase your daily step count by 10% each week until you reach the recommended 10,000 steps per day. You may also want to take advantage of new fitness tracking devices (like Fitbit, Up, Jawbone), which can help monitor your daily steps. If you would like to take part in more structured exercise the following table displays some current recommendations.

Type	Frequency	Intensity	Duration
Aerobic Exercises Involves rhythmic activity of large muscle groups that can be continuously maintained. Examples include walking, jogging, cycling, rowing, swimming. **Goal:** Increase physical fitness; reduce cardiovascular risk.	5 or more days per week	Moderate – Hard (RPE 12 -15; you should increase in heart rate and breathing)	Aim for 30 minutes or more
Resistance Exercises Involves weight or resistance using free weights, weight machines, resistance bands, medicine balls or your own body weight. **Goal:** Increase muscle mass and muscle strength.	2 to 3 days per week (non consecutive days)	Moderate – Hard (RPE 12 -15; 60 – 80% of the maximum weight you can lift only once)	8 – 10 exercises targeting upper and lower body large muscle groups 10 – 15 repetitions
Flexibility Exercises Can be static or dynamic **Goal:** Increase range of motion; reduce exercise-related injury risk.	2 or more days per week (perform on the same days as aerobic or resistance exercises)		10 minutes targeting major muscle groups Hold each static stretch for 10-30s Repeat each stretch 3 – 4 times
Balance Exercises Balance exercises include walking backwards, heel toe walking in a straight line or standing on one leg at a time. **Goal:** Fall prevention	3 or more days per week		

Table 1. **Exercise guidelines for Chronic Kidney Disease. Adapted from Kirkman *et al*. (2014). Based on American Heart Association and American College of Sports Medicine recommendations for physical activity.**

Exercising during dialysis is a safe and convenient option to increase your activity in a supervised setting when you would otherwise be sedentary. Some dialysis units may have access to stationary cycling equipment specifically designed to fit on the end of a dialysis chair. Speak to your healthcare providers to establish if this is a viable option for you.

Using the Rating of Perceived Exertion (RPE) scale (Table 2) is a good method to monitor the intensity of your activity. Ideally you should ensure that your activity is intense enough for you to benefit from without overdoing it. The RPE scale rates how difficult you feel the exercise to be and ranges from 6 (no exertion at all) to 20 (maximal exertion). The optimal activity intensity should range from 12 (somewhat hard) to 15 (hard).

Safety Considerations: Be aware of the following when exercising:

- Stop any activity if you experience chest pain, dizziness or unusual shortness of breath.
- Sometimes you may have increased thirst levels when increasing your physical activity. Be aware of your fluid restrictions.
- Monitor you blood glucose closely during any activity if you are diabetic.

Slow your activity down if:

- You feel very tired or not able to continue.
- You are too breathless to talk.
- You do not feel fully recovered after one hour.
- You have an unusually high heart rate.

Rating of Perceived Exertion		
6		Little or no effort. How you feel lying in bed or sitting in a chair. Can talk or sing easily without feeling breathless.
7	Extremely Light	
8	Very Light	
9		
10		
11	Fairly Light	
12		Target Range How you should feel with activity and excise Can just comfortably talk and not sing without gasping for breaths
13	Somewhat Hard	
14		
15	Hard	
16		How you feel with the hardest work you have ever done. Cannot say more than a few words without gasping for breath. Don't work this hard!
17	Very Hard	
18		
19	Extremely Hard	
20		

Table 2. Borg's Ratings of Perceived Exertion Scale. Adapted from Kirkman *et al*. (2014).

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