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7,000 RARE DISEASES



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DIALYSIS PATIENTS



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THE KI NEY CITIZEN



A publication of Dialysis Patient Citizens (DPC) Education Center

When "I" is
replaced with "We"
even illness
becomes wellness.

- Malcolm X

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On behalf of the Board of Directors, staff and volunteers for Dialysis Patient Citizens (DPC) Education Center, I want to thank the kidney community for its continued support. I would also like to personally express my appreciation to all of you who so generously help us advance our mission. Without your help and the broad support of the kidney community, we would not be able to carry out our vital mission.



As a kidney failure patient myself, I know firsthand the importance of patient education and the critical role it plays in improving our health. In fact, I often tell others that “when you know better, you do better.” That passion for patient education, which I share with the rest of our Board, helped lead to the formation the DPC Education Center and its mission to empower individuals through education to improve kidney patients’ quality of life and reduce the occurrence of end stage renal disease (ESRD).

With that said, we need your continued assistance to carry out and fulfill our mission. One way that you can make a difference, is to mail in a contribution in the enclosed envelope today. Your donation will go directly to our efforts to raise awareness about kidney disease as we work to delay and hopefully prevent kidney failure in others. We thank and appreciate every individual that has given, and continues to give, to our mission.

Your contribution will go a long way in helping us fulfill our mission at the DPC Education Center. In 2015, we created a new Advisory Council with leaders from the kidney community and beyond, who provide us with expertise in the formation and review of the educational resources that we provide. We developed new mental health handouts in association with the American Psychological Association and participated in critical forums on health literacy and mental health. We also made the DPC Education Center website more responsive and easier to use on smart phones and tablets. Finally, we launched this new print newsletter, “The Kidney Citizen.”

While we had many successes in 2015, our work is far from done. In 2016, we have many goals to help us expand our mission. Some of our priorities include improving access to cutting edge patient-driven educational materials, providing additional resources and trainings for patients to become more active in their care, and continuing to collaborate with partners to bring the best ideas to the table to advance patient care. We will also continue to provide programs that help advance patient choice, prevent and delay the onset of kidney disease, and improve health outcomes.

We also need your help in getting out our critical information. We encourage you to participate in and spread the word about our educational offerings. Only through education can we empower people to make the right decisions regarding their health. 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
 Board President

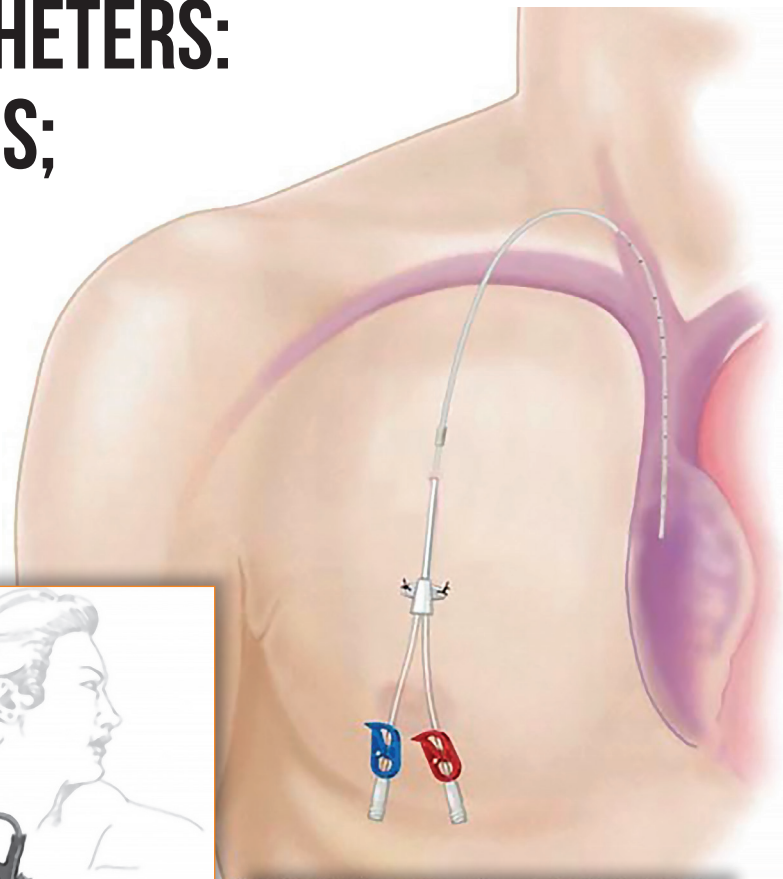
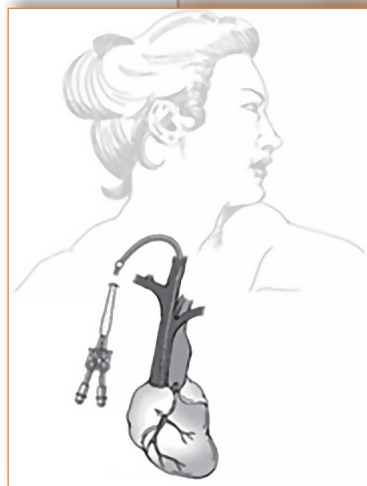
LONG TERM DIALYSIS CATHETERS: A THREAT TO YOUR ACCESS; A THREAT TO YOUR LIFE

By **Steven Curtiss, M.D., F.A.C.S.**

It is well established that the safest and most durable dialysis access is an arteriovenous (AV) fistula which is constructed by connecting a patient's artery to vein. Unfortunately, sometimes a patient's renal disease is discovered when the person is on the verge of dialysis. The progression of chronic kidney disease is unpredictable. In these situations, there may not be time for creation and maturation of an AV fistula and if the patients' preference is for hemodialysis, the patient may require a dialysis catheter. Catheters are usually tunneled under the skin of the chest wall into large veins in the neck. Dialysis catheters can provide life-saving emergency dialysis, but they also create significant short-term and long-term problems that patients should understand.

First, catheters carry a significant risk of life-threatening infection, because they provide a direct pathway for bacteria to travel from the outside world into the blood stream. In fact, one quarter of dialysis patients with a catheter as long as one year will have a life threatening infection. Since these catheters have a large diameter, they often lead to clotting or narrowing in the large veins in the neck or chest. This is significant because these veins are very important for the proper function of dialysis accesses created in the arm. So, the presence of a long term catheter may limit further dialysis options. Catheters also present a psychological barrier for patients and staff because they don't require cannulation with needles and may serve as a crutch -- discouraging the use of a recently created AV fistula.

Although temporary dialysis catheters can be lifesaving in the appropriate situation, they should be thought of as a temporary bridge to an AV fistula or graft or peritoneal dialysis catheter as appropriate. The best way for patients who prefer hemodialysis is to avoid the need for a dialysis catheter is to have an AV fistula created long before dialysis is needed. Ideally, an AV fistula can be created at least 6 months before dialysis is anticipated. This requires that the patient's veins be preserved for eventual access. All patients with any degree of renal disease (even those not even close to requiring dialysis or who prefer peritoneal dialysis or are planning a pre-emptive kidney trans-



plant), should avoid blood draws and IVs in one arm, generally the non-dominant arm or the arm opposite a pacemaker or defibrillator. This will give the access surgeon a good vein to work with. PICC lines should be avoided even in the arm that is not being saved because they often cause clotting of the veins. Furthermore, if a patient is being considered for a pacemaker, mediport or implantable defibrillator, this decision needs to be made by taking current or future dialysis access into account. The Nephrologist and Access surgeon should be part of this decision making process. Peritoneal dialysis can also be considered as a bridge until an access is mature and may be a much safer alternative or as a plan for long-term treatment for the patient.

Dialysis catheters provide a very important short term function, but patients should be aware of their high complication rates, including infections and clotting. For these reasons, catheters should not be a substitute for placement of an AV fistula or graft, better and safer forms of dialysis access. ■

CYSTINOSIS, ONE OF 7,000 RARE DISEASES

By **Terri Schleuder**

VP of Education & Awareness, Cystinosis Research Network

Statistically, there are over 7,000 rare diseases in the United States that collectively impact 30,000,000 people. This is the story about one of them, and an **important one for kidney disease patients as nearly all cystinosis patients lose their kidney function. Also, recent data suggests a high incidence of underdiagnosis and carriers among dialysis patients.**

Nephropathic Cystinosis is a rare metabolic, genetic disease that affects about 500 people in the U. S. and about 2,000 worldwide. Cystinosis occurs in a child when he/she inherits the recessive gene, identified in the late 1990's as the CTNS gene, from each parent. In the general population, only 1 in 200 people carry this gene -- but if two carriers of the CTNS gene produce a child, there is a 25% chance that the child will have Cystinosis. This occurs in about 1 of every 250,000 births. It is very rare!

Our family became one of these statistics when our youngest son, Steve, was born in 1988.

The defect that causes Cystinosis is at the cellular level. Cystinosis occurs when an amino acid called cystine gets trapped inside a part of the cell called the lysosome. Think of it as a one-way door. The cystine gets into the lysosome, but because of the defect it cannot get back out. This causes a build-up of cystine that forms crystals within the cell that damages and eventually destroys cell function.

Virtually all the cells are impacted in Cystinosis and eventually many organs in the body are damaged. The kidney and



Adults with Cystinosis at the 2015 CRN Family Conference held in Chicago in July. Steve is seated, the first one on the right.

eye are more severely damaged early on. In the kidney, the ability to reabsorb water and crucial electrolytes (such as sodium, potassium, bicarbonate and others necessary for normal body functioning) are lost, spilling out into the urine. This process is called Fanconi Syndrome. Cystinosis is the leading cause of Fanconi Syndrome in children. In the eye, the cystine forms crystals in the cornea that cause severe photophobia (sensitivity to light) and painful corneal ruptures. Left untreated, blindness can result.

Hallmarks of Infantile Nephropathic Cystinosis in the first year of life are dehydration, polyuria (need to pass a lot of urine every day) and an unquenchable thirst. Due to the kidneys' inability to balance calcium and phosphorus, infant's bones do not develop normally, resulting in Rickets. Infants with Cystinosis often have no appetite, though what is consumed is usually salty or spicy. Infants may experience frequent vomiting (2-5 times daily). Children who appeared normal at birth, stop growing, lose weight and quickly fall below the 3rd percentile on growth charts. This is called failure to thrive.

Our son, Steve, began to show all of these symptoms between 6 and 9 months of age. He progressively got worse as time passed. Repeated trips to doctors and specialists yielded more questions than answers. In July 1989, when he was 18 months old, his weight had dropped to less than 15 lbs. His skin hung in loose folds. His hair had started to fall out. His huge blue eyes had big dark circles under them and his lips and mouth were always dry, no matter how much water he drank (which was a lot, more than an adult).



Teens with Cystinosis attending the Global Genes sponsored Teen Adventure as part of the CRN Family Conference in Chicago. Dr. William Gahl and Dr. Craig Langman are holding the sign.



People living with Cystinosis who attended the 2015 CRN Family Conference in Chicago, July 16-18

The fear I felt at that time was all consuming. I knew if we didn't find an answer soon, he would die. I prayed constantly. Finally, as he began to show signs of kidney failure, we found our way to the Pediatric Nephrology Department at the University of Michigan Health Care System. Based on his symptoms, labs, and a specialized blood test called a white cell cystine level, he was diagnosed quickly. At this facility, they had seen Cystinosis before. Steve's symptoms were classic.

While we felt happy to finally know what it was he had, the more we learned, the more terrified we became. This disease became our fork in the road --our before and after. Everything in our lives after his diagnosis would be viewed through the lens of Cystinosis.

Before the late 1970's, children born with Cystinosis died by the age of 9 or 10 from kidney failure. With advances in medical research, dialysis, and kidney transplantation, they started to live into adolescence and beyond. At about this same time, research proved a drug called Cysteamine could remove cystine from cells. It did this by attaching to the cystine within the cell, thereby changing the shape of the molecule and allowing it to leave the lysosome through a different "door" or pathway. *Steve was started on this research study with Cysteamine when he was diagnosed and improved over time. The downsides of the drug were that it tasted and smelled like sulfur (rotten eggs) and had to be given every 6 hours around the clock to be effective in removing cystine from cells. In addition, it caused severe stomach irritation.*

In 1994, Cysteamine was FDA approved as the first successful treatment for those with Cystinosis under the brand name Cystagon. It still needed to be taken every 6 hours.

In spite of our best efforts and compliance with the medication regimen, Steve developed end stage renal failure at about age 10 ½ years of age. He was on hemodialysis for about 6 weeks before receiving a living related donor transplant in June 1999 at age 11. I was blessed to be a close enough match to be his donor. Since then he has been mostly stable. While some meds changed, he still takes many doses every day. He finished high

school, graduated from college, and is currently working part time with a goal of being independent and living on his own in the near future. We try very hard to focus on the positive and see the beauty in ordinary days.

In 2012, a delayed release version of Cysteamine, Procsybi, was FDA approved and only has to be given every 12 hours to be effective. This has improved the quality of life and increased compliance in many people.

About the same time, in 2012, an eye drop containing Cysteamine was FDA approved as Cystaran. Though it has to be given hourly during waking hours (10-12 times daily), it has proved successful in dissolving the cystine crystals in the cornea.

It has been over 20 years since Cysteamine was first FDA approved. This treatment has proved successful in slowing the progression of the disease. It allowed many who have Cystinosis to

reach late adolescence or adulthood before needing a kidney transplant, but it is still just a treatment -- not a cure.

While many people are living longer, many still experience late complications including muscle wasting, male infertility, bone issues, difficulty swallowing, pulmonary, thyroid and central nervous system problems. Clearly, research on Cystinosis needs to continue.

We in the Cystinosis community remain hopeful and vigilant and continue to do all we can to increase awareness, educate doctors, health care professionals and the public, and raise funds to support promising research that will ultimately lead to a cure. Research has already raised Cystinosis from a disease of despair to one of hope, and perhaps someday no child or family will suffer from the ravages of this disease.

There have been many lessons I have learned on this now 27-year journey with Cystinosis. The 'Truth' that stays close to my heart always, is knowing that value, beauty and quality of a life are not measured in years, but in the number of lives touched. The beauty of the lives of our loved ones with Cystinosis is immense.

To learn more about Cystinosis, please visit CRN's website at <https://cystinosis.org/> ■

DID YOU KNOW?

Nearly all cystinosis patients develop kidney failure.

Many more dialysis patients are now believed to carry the cystinosis gene.

IS THIS THE FUTURE OF ESRD CARE?

A NEW PROGRAM GOES THE EXTRA MILE FOR DIALYSIS PATIENTS

By **Jackson Williams**

Government Affairs Director, Dialysis Patient Citizens

For more than a decade, officials in Washington, DC have been experimenting with ways to reorganize Medicare to deliver better care at lower costs. Several of these “demonstration projects” have involved ESRD patients. Now, the largest such program for dialysis patients has kicked off at 13 locations across the U.S. It’s called the ESRD Seamless Care Organization, or “ESCO,” model. This article describes what one of these projects, Philadelphia-Camden Integrated Kidney Care, is doing to improve care for its patients.



Philadelphia-Camden Integrated Kidney Care covers about 2,000 patients at DaVita clinics in the Philadelphia area. Patients do not enroll in an ESCO; they are assigned to one by Medicare based on where they go to dialyze. Once the patient is assigned, the ESCO is responsible for the total cost of care for the patient—not just dialysis and other services associated with kidney care, but for emergency room visits and inpatient hospitalizations that make up the bulk of treatment costs for ESRD patients.

The ESCO agrees to actually lower its patients’ costs relative to the national average. To do so, it must keep patients’ health stable and avoid preventable complications that send patients to the hospital.

To accomplish this, Philadelphia-Camden Integrated Kidney Care deploys an additional staff of 20 clinicians and care coordinators. These teams aim to provide a “total care package,” says Bridget McCoy, a nurse practitioner who leads one of them. McCoy, who was previously assigned to regular duties in a dialysis facility, recalled that in that role, “there were things I wanted to do for my patients that I couldn’t do



before,” because clinics are organized to provide only the renal treatment specified by Medicare.

Under the regular system, accountability is fragmented; dialysis clinics and nephrologists are responsible for kidney care, primary care physicians are responsible for other illnesses such as diabetes, and hospitals are responsible for the care provided within their walls. Under the ESCO system, the ESCO team commits to filling “holes in care.” “Most patients like it,” says McCoy. “It feels like a concierge.”

Like a concierge at a hotel, ESCO care managers use their special knowledge and contacts to provide a smooth, hassle-free experience to clients. But instead of securing dinner reservations or theatre tickets, the care manager is on the phone making doctor appointments, getting answers from pharmacists, or cutting through red tape with dentists or state assistance programs. And the stakes are higher, because a missed appointment or medication dosage can snowball into a trip to the hospital. “The extra step makes the difference,” says McCoy.

Among the key tasks that Philadelphia-Camden Integrated Kidney Care undertakes are:

Transitions from the hospital to the community. A key goal of the care team is understanding why a patient was hospitalized and intervening to prevent another one. Often dialysis clinics have difficulty obtaining discharge summaries from hospitals, but the ESCO's dedicated care coordinators are able to build relationships that expedite sharing of information.

To completely follow through on items in a discharge summary can take up to three hours of work, says McCoy, and many patients can be so overwhelmed at the prospect that they throw up their arms and give up. Follow-up items typically include changes to existing medications, prescriptions of new medications, and referrals to new specialists. ESCO care managers are able to explain the new medication regimen to the patient, make sure new prescriptions are filled, identify specialists who are taking new Medicare patients, make appointments, and arrange for transportation if necessary.

Medication reconciliation. A pharmacist is part of Philadelphia-Camden Integrated Kidney Care's ESCO team and is available to consult on issues of "polypharmacy"—too many medications that may have interactions or serious side effects. One patient who was asked to bring in his prescriptions for reconciliation arrived with a "bucket of medications," says McCoy. With the help of the pharmacists, the team was able to eliminate four prescriptions from the patient's regimen.

Managing co-morbidities. The Philadelphia-Camden team has found that many patients whose kidney care has been stable have neglected managing their diabetes. ESRD patients are seen continuously by their kidney care team but do not always visit their primary care physicians regularly. As a hub of holistic care for ESRD patients, the ESCO team tries to coordinate care of comorbidities like diabetes, when necessary providing referral options for primary care physicians experienced with ESRD, or nudging patients to get eye and foot examinations. Occasionally, the Philadelphia-Camden team has had to track down a doctor who has moved to a new office since the last time the patient visited.

Involving clinicians at the dialysis facility. The Integrated Care team regularly meets with the team at each facility to review patients' lab results, discuss any issues or barriers that individual patients may be facing, and identify patients most at risk for hospitalization. Working together they can reinforce each other's messages to patients.

Engaging patients in their care. Dialysis patients assigned to an ESCO are informed by a letter, telling them that "The goal of an ESCO is for your dialysis facilities, nephrologists, and other health care providers to communicate closely with your other health care providers, so they can deliver high-quality care that meets your individual needs and preferences." Patients are told they will now have a specially trained nurse available to them who "will work with you, your family, dialysis team, doc-

tors and care partners, both inside and outside of the dialysis center, to help you better understand and manage your ESRD." Patients are also reminded that they can still choose any dialysis facility, doctor, or hospital. The letter is followed by an individual consultation with the nurse practitioner.

While the ESCO team takes on many tasks, improved outcomes can't be achieved without the active cooperation of the patient. For many patients this can involve a real commitment, such as agreeing to additional time on dialysis when it's necessary to remove fluids. At the Philadelphia site, about seventy percent of patients are fully engaged in the program, and very few have declined to participate at all. But the clinical staff is aware that ESRD patients already have a rigorous treatment regimen to follow, and are "not looking for additional opportunities to engage the health care system," as McCoy put it. "You pick your battles." Another nurse practitioner, Karol Eccles, says that patients are receptive, if not always immediately. "It takes time to build trust with patients."

One hiccup that ESCOs face is that rules in the Medicare program prohibit providers from channeling patients to specific doctors or facilities, even if they're part of an informal network cooperating in the care of a group of patients.

Medicare does not pay extra for the ESCOs. Each ESCO, which is a partnership between a dialysis organization and a nephrology practice, must invest its own money in hiring the integrated care team and providing additional time on dialysis. If the ESCO "beats" the cost of serving the average dialysis patient by keeping its patients well, the dollars saved are shared between the Medicare program and the ESCO. The Philadelphia-Camden Integrated Kidney Care ESCO is reasonably confident it will succeed financially because DaVita's integrated care subsidiary, Village Health, has used many of the same techniques in its partnerships with insurance companies, including its own Special Needs Plan that it operates for Medicare in Southern California and Nevada.

What does the future hold for this new model of care? DPC believes all ESRD patients deserve a better healthcare experience and improved quality of life that integrated care can provide. However, the challenging economics and stringent rules that Medicare imposes on the ESCO program have scared away potential participants. Many kidney care advocates, including DPC, strongly support integrated care for all ESRD patients and legislation that would enable a far greater number of ESRD patients to receive the gift of integrated care. The ESRD Integrated Care Program, contained in legislation currently being drafted by Members of Congress, would deliver the same care coordination as ESCOs, provide enhanced benefits, and address the main challenges ESCOs face in expanding to more service areas.■

CALL TO ACTION

Dialysis patients and their family members have been advocating to open Medicare Advantage for the past year and we are pleased to announce some great progress.

Recently, the Senate Chronic Care Working Group released a series of policy proposals which included language providing dialysis patients access to Medicare Advantage Plans. After asking for comment from interested parties, organizations throughout the healthcare community including interest groups, think tanks and patient organizations expressed support for the working group's proposal to allow dialysis patient enrollment in Medicare Advantage Plans.

This is great progress toward improving care for dialysis patients across the country, but that doesn't mean it's time to relax. We need to keep the pressure on legislators to repeal the discriminatory policy that prevents dialysis patients from enrolling in Medicare Advantage plans. These plans could lower patient's out-of-pocket costs while providing greater care coordination and better health outcomes.

Take a moment to contact your legislators today by visiting our legislative action center or by calling the congressional switchboard with your message.

ONLINE

Visit www.dialysispatients.org/take-action

Step 1 Click the issue labeled "Open Medicare Part C to Dialysis Patients", then hit Take Action

Step 2 Enter your email and zip code (your full address may be required to determine your representative)

Step 3 Add your personal story in the letter if you choose

Step 4 Click Send

BY PHONE

Contact the **Capitol Switchboard** at **(202) 224-3121**
 Sample points to make when you call:

- My name is **[YOUR NAME]**. I am a dialysis patient and I live in **[CITY or TOWN NAME]**.
- I'm calling to encourage you to support measures that open Medicare Advantage Plans to dialysis patients like myself.
- Medicare Advantage will reduce my out-of-pocket cost.
- Also, Medicare Advantage plans can provide greater coordination of care options which improves my health and can help to keep me out of the hospital.



Legislative Action Center

ACTIVE ISSUES | ADVOCATE'S TOOLBOX | LOOK UP OFFICIALS | ACTIVITY TRACKER

Active Issues

Federal Issues

Urge your Members of Congress to support the Living Donor Protection Act
 Living organ donation saves lives and helps reduce the amount spent on kidney dialysis and other medical treatments. The Living Donor Protection Act (S. 2584/H.R. 4616) sponsored by Representative Burgess, Representative Nadler, Senator Kirk and Senator...

[+] more

Ask your legislators to support The Access to Marketplace Insurance Act (H.R. 3742)
 Organizations like the American Kidney Fund (AKF) provide financial assistance to dialysis patients who are unable to pay their insurance premiums. Recently, insurers have refused to accept these premium payments in states across the U.S. Fortunately, new legislation has...

[+] more

Open Medicare Part C to People on Dialysis
 Background: Medicare Part C plans (otherwise known as Medicare Advantage plans) are private insurance policies that must be equivalent in coverage to Medicare Parts A (hospitals) and B (doctors, nurses and dialysis). These plans sometimes offer more generous benefits than...

[+] more

Urge Your Members of Congress to Support the Kidney Bill (S. 598/H.R. 1130)
 The Chronic Kidney Disease Improvement in Research and Treatment Act (S. 598/H.R. 1130) has been introduced in the U.S. Congress to improve federal policy related to caring for individuals with chronic kidney disease by addressing gaps in critical research; improve...

[+] more

State Issues

Protect Medicaid Funding in Louisiana
 The state of Louisiana is currently facing a budget shortfall of \$750 million for this fiscal year. In order to close this gap, a proposal has been submitted to eliminate all optional Medicaid benefits including funding for dialysis, hospice, pharmacy and other important...

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PAIRED KIDNEY DONATION AT CHRISTIANA CARE HEALTH SYSTEM, CHRISTIANA CARE KIDNEY TRANSPLANT PROGRAM

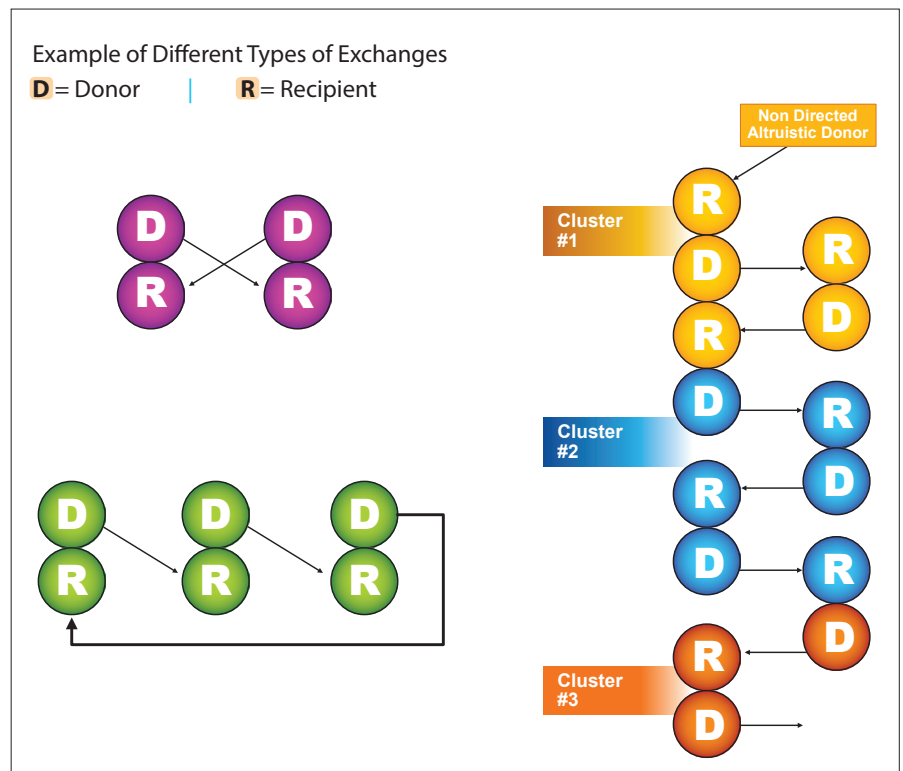
By **Emily Pruitt** RN, MSN
Living Donor Coordinator,
Christiana Care Health System

Paired Kidney Donation is an alternative option given to those who are not directly compatible with their recipient. Christiana Care Health System (CCHS) Kidney Transplant Program participates in Paired Kidney Donation, which allows an incompatible donor to still help their loved one who is in need of a kidney transplant.

Paired Kidney Donation, formerly referred to as a “Donor Swap” allows more recipients to have the benefit of living donor kidneys and provides a way for motivated, healthy living donors to still help his or her potential recipient. Essentially, Paired Kidney Donation works by allowing a blood type or crossmatch incompatible kidney transplant recipient and their donor to exchange kidneys with other donor/recipient pairs who are also incompatible. In other words, the two pairs swap kidneys to make compatible donor/recipient pairs. More often the Paired Kidney Donation programs make “chains” with the living donors and recipients, in order to help the most number of people at one time.

Paired Kidney Donation allows the recipient to have all of the benefits of living donation even if their loved one is not a match to them. Some benefits of living donation include:

- Significantly better short and long term survival rates for transplants from living donors than transplants from deceased donors.
- The recipient has time to plan for the transplant.
- The surgery can be scheduled at a mutually-agreed upon time rather than performed on an emergency basis.
- Even with Paired Kidney Donation, perhaps the most important aspect of living donation is the psychological benefit.



The recipient can experience positive feelings knowing that the gift came from a loved one or a caring stranger. The donor experiences the satisfaction of knowing that he or she has contributed to the improved health of the recipient.

Facts about Paired Kidney Donation:

- In order to participate in Paired Kidney Donation, each recipient must have a living donor who is willing to participate in the Paired Kidney Donation program and has been cleared as a living kidney donor.
- The evaluation of the potential donor is the same as for a donor who is planning for a direct living donor surgery.
- Although we work with other transplant programs across the United States to find compatible donors and recipients for the CCHS recipients and donors, the surgery of the CCHS recipient and living donor will be at CCHS. ■

DOCTOR, WILL I NEED TO GO ON DIALYSIS?"



By **William Dahms Jr., DO, FASN**

That has to be the most common question I encounter in my everyday practice. It's something that is often asked as soon as I am done exchanging greetings with a patient in the office or hospital setting. There always seems to be some degree of trepidation when patients are referred to a kidney doctor. There is the fear that they will end up being diagnosed with kidney failure, and therefore condemned to being "hooked to a machine" for the rest of their days. Certainly, one of the worst parts of my job is telling a patient and his or her family that I am recommending starting dialysis. It is something that I would not wish on anybody. In 2016, however, the news isn't all bad! As a practicing nephrologist for over 10 years, we have seen many improvements in the care of the patient with chronic kidney disease (CKD), and we have been able to prolong the lifespan of native kidney function and defer the need for dialysis.

How do we do it? In general, we would like to treat the underlying cause of kidney failure whenever possible. So, if CKD is related to diabetes and hypertension, for example, those problems need to be aggressively treated and controlled. The earlier that this is accomplished, the better the outcome. There

are several studies now that have demonstrated the preservation of kidney function in diabetic and non-diabetic kidney disease using medications known as angiotensin converting enzyme (ACE) inhibitors and angiotensin receptor blockers (ARBs). As anti-hypertensive medications, these compounds have been shown to preserve kidney function independent of their effect on lowering blood pressure. If any patient shows up in my office with diabetes, hypertension and elevated urine protein levels, they will be highly encouraged to start an ACE inhibitor or ARB if not already taking one. ACE inhibitors have also been shown to be beneficial in treating CKD attributed to other primary kidney disorders including IgA nephropathy and membranous nephropathy.

Recently, the class of cholesterol lowering medications known as "statins" has also garnered attention in the nephrology world. These medications have been shown to have a renal preserving effect in patients with CKD independent of the effect on lowering cholesterol. In fact, it is now often recommended that patients with CKD stage 3 or greater be placed on a statin medication barring any history of previous intolerance or allergic reaction. This is especially true if the patient has a history of any heart or vascular disease.

For patients with genetic kidney disorders such as polycystic

kidney disease (PKD), there has been a relative lack of data suggesting any one medication that has proven to be beneficial in slowing progression to dialysis dependent kidney failure. Again, ACE inhibitors have been shown to be effective in controlling blood pressure in PKD patients, but without as great an effect on kidney preservation as in other patient groups. There is great hope that newer compounds will soon be available to slow the loss of kidney function in PKD. Trials are currently underway looking at the vasopressin receptor antagonist tolvaptan and its effects in PKD patients. This is a medication already being used to treat PKD in other parts of the world. Many in the nephrology community (including myself) are optimistic that tolvaptan will receive FDA approval for use in PKD patients within the next few years.

Finally, it is worth mentioning some other non-traditional approaches to preventing CKD progression. Data have shown that vitamin D has been able to reduce proteinuria in patients with CKD. Sodium bicarbonate has also been shown to preserve kidney function in CKD patients with low bicarbonate levels compared to placebo.

In addition to all the beneficial things we can tell a patient to take in an effort to preserve their kidney function, I should also point out some of the things to avoid which may worsen existing kidney disease. The pain medications known as non-steroidal anti-inflammatory drugs (NSAIDs) and COX-2 inhibitors can cause transient worsening in kidney function. While they are helpful in reducing pain, they are not re-recommended for chronic use in CKD patients. One tablet on its own may not have any lasting effect, but long term exposure can worsen kidney function, raise blood pressure, and contribute to fluid retention. I generally recommend that all of my patients with CKD avoid these preparations. Most types of intravenous contrast (IV dye) used for cardiovascular procedures and CT scan testing can also cause a transient worsening in kidney function. Before being exposed to any contrast, a patient with CKD should consult with his or her nephrologist, as there are ways to prophylactically prevent worsening kidney function after dye exposure. Much has been learned about gadolinium, another type of contrast specifically used for MRI studies, in recent years. In general, gadolinium should not harm kidney function in patients with CKD. It is more dangerous for use in patients who are already on dialysis.

Finally, we have seen studies in recent years suggesting the possibility of severe kidney damage from the use of oral sodium phosphate based preparations used for colonoscopies or as laxatives. Patients with CKD should not be given these agents. The good news is that there are now many other safer options that can be given prior to colonoscopy. Be sure to discuss any diagnosis of CKD with your gastroenterologist before taking a colon cleansing preparation.



Of course, it goes without saying that for all patients with CKD, remaining in close contact with the nephrologist is essential. No two patients are exactly the same. In my experience, I have looked for certain patient characteristics that serve as “red flags” for progressive kidney failure. Among these are: uncontrolled blood pressure, elevated urine protein excretion, and family history of kidney disease requiring dialysis. Notice that the level of creatinine isn’t always the biggest determinant of progressive kidney failure, yet this is often the abnormal finding that will get a patient referred for nephrology evaluation. Certainly, patients who have some or all of the above risk factors are at the highest risk for progressive kidney failure. We will always try to use the strategies mentioned above (ACE inhibitors, ARBs, statins) to mitigate these risk factors.

As the old saying goes, an ounce of prevention is worth a pound of cure! This is certainly true with CKD, and hopefully we can look forward to prolonging the renal function of our patients for years to come.■

IMPROVING MENTAL HEALTH CARE OF KIDNEY DISEASE PATIENTS: A CALL FOR ACTION

By **Molly Phillips**, MPH, MSW, **Barry Smith**, MD, PhD, **Pamela Hoyt-Hudson**, BSN, RN, and **Jennifer Melendez**, BA, CHC, CHRC, CIP (all from The Rogosin Institute)

The following article was submitted by the Rogosin Institute. It highlights their work to meet both the physical and emotional needs of their patients. Talk to your dialysis facility about the resources that may be available to you.

In a recent conversation between a staff member at the Rogosin Institute and a dialysis patient in Brooklyn, the patient shared that at 37, she had been on dialysis for over 15 years after a diagnosis of nephrotic syndrome in her late teens. Years ago, a family member donated a kidney. However, after only two years, the transplant failed. In addition to telling the staffer about how much she was struggling to stabilize her blood pressure and how frustrated she was following multiple hospitalizations in the preceding two months, she shared that she had recently lost her uncle to cancer, that she had to move apartments and was unsure how she could afford the move, and that she was fighting with her mother, among other stressors.

This patient's experience is a perfect reminder that we cannot possibly expect End Stage Renal Disease (ESRD) patients to follow their complex healthcare plans if they are concerned about rent, have little social support, or have other life stressors beyond their dialysis care. As health-

care providers, we must do a better job at addressing the socio-economic needs of our patients by connecting them to resources and organizations that can help. We must also recognize the many factors that influence adherence to treatment and provide more comprehensive mental health care to our patients. We must enhance opportunities for



communication and work with patients as partners. Depression, anxiety, and stress among dialysis patients are incredibly prevalent, and as providers, we can – and should – do more to support the whole person, including their mental and emotional health needs. Dialysis patients are not defined by dialysis or ESRD, but rather by everything that makes them unique human beings, just like all of us.

Research suggests that over one third of hemodialysis patients experience clinical depression (Palmer et al, 2013), and around half of patients experience anxiety (Cukor, 2008 and Feroze, 2012). The Centers for Medicare and Medicaid Services recently acknowledged that depression is all too common and ignored among ESRD patients. With this in mind, this year, CMS is requiring dialysis units to screen patients for depression. But simply screening patients is not enough: we must have adequate follow-up plans in place for patients who need treatment and further support.

In recognition of the need to better address the mental health needs of dialysis patients, in October 2015, the Jack J. Dreyfus Center for Health Action and Policy (CHAP) at The Rogosin Institute convened a Roundtable discussion with experts in the field of mental health, depression, and kidney disease entitled

“Mental Health as it Relates to Individuals with Chronic Kidney Disease and End Stage Renal Disease.” The Roundtable brought together patient activists and healthcare providers, including nephrologists, psychologists, a psychiatrist, a social worker, an art therapist, a nurse, a healthcare administrator. The goal of the Roundtable was to define the challenges related to mental health and kidney disease patients and to leave with multiple ideas for pilot projects to be implemented at The Rogosin Institute and with partners across the country to begin to address the defined problems.

The day began with a brief introduction to The Rogosin Institute, followed by a presentation on the current state of research related to kidney disease and mental health by Dr. Rajnish Mehrotra from University of Washington Division of Nephrology and leader of a multi-site research study on depression and ESRD patients. Following the presentation, Roundtable participants engaged in a robust discussion about the mental health challenges impacting kidney disease patients. Issues identified included:

- Insufficient support and empowerment of patients, particularly during the first 120 days of dialysis
- Few opportunities for peer-to-peer learning and patient engagement
- Limited education about mental health needs
- Stigma around mental health issues
- Staffing challenges, particularly staff burnout and the burden of administrative tasks on social workers, limiting their ability to provide counseling
- Limited research and understanding of mental health issues among chronic disease patients and their families

In addition to the issues identified by the Roundtable participants from the provider and patient activist point of view, the Rogosin CHAP team had conducted in-depth interviews with 29 patients from six dialysis units in Brooklyn, Manhattan, and Queens in New York City prior to the event. Interviews included questions related to experience with kidney disease, stressors, patient self-efficacy (confidence in their abilities to manage their disease), support systems, and coping mechanisms.



Interviewees ranged in age from 37 to 86, just over half were female, and they came from diverse racial and cultural backgrounds. Interviewees had been on dialysis for varying lengths of time, ranging from three months to 27 years.

When asked how dialysis had changed their lives, many respondents shared their concerns, including that of the limitations on their ability to work and travel, the burden of the time commitment required by dialysis insomnia and a lack of enjoyment in activities important to them. However, others acknowledged that dialysis kept them alive and gave them a second chance at life. When asked about coping mechanisms, interviewees shared watching TV, listening to music, walking, turning to friends and family for support, relying on prayer or meditation, and engaging in hobbies or crafts. Some interviewees shared that support groups or counseling sessions had helped them cope with their diagnosis and the demands of dialysis. Using the PHQ-9 depression screening tool, the investigators found that approximately one third of patients interviewed had mild depression and close to 20% more scored as having moderate to severe depression.

Patients were also asked about what could be done to help them better manage their physical and mental healthcare needs. Responses included additional support groups, patient appreciation days at the dialysis units, more information about treatment choices, and more upstream education about the risk factors for and prevention of chronic kidney disease.

With the concerns and suggestions highlighted by the patient interviews and provider perspectives in mind, Roundtable participants looked at the issues identified during the group discussion and developed actionable ideas for projects to address the mental health challenges impacting dialysis and chronic kidney disease patients. By the end of the day, participants left with the following list of project ideas for implementation at Rogosin and around the country:

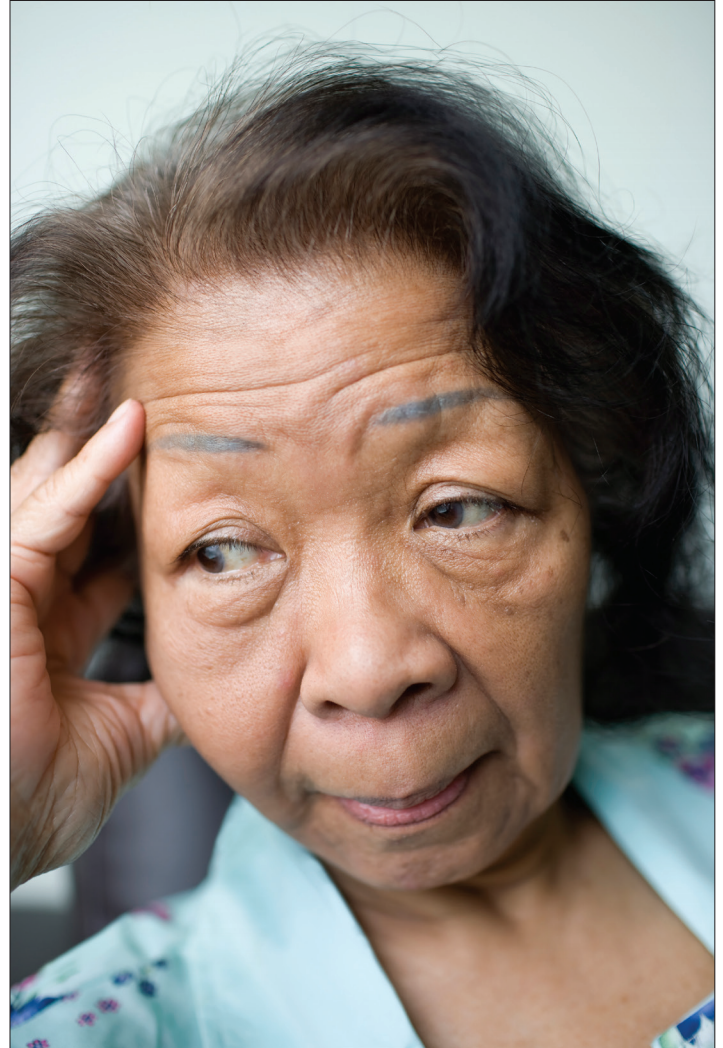
1. A needs assessment to better understand patient mental health needs and openness to counseling or other treatment.
2. Increased staff support and training around patient



- mental health needs, including reconfiguration of the social workers' roles, allowing them to spend less time on administrative tasks and more time with patients.
3. Increased patient and family support, including peer mentoring and enhanced support during the first 120 days of dialysis treatment.
 4. The creation of a mental health toolkit for patients that could be used during treatment or at home. The toolkit could include creative arts activities, mindfulness and breathing techniques, recreational therapy, and educational materials.
 5. An awareness campaign to address stigma and reframe mental health in a positive light – shifting the emphasis from mental illness to mental health.

Since hosting the roundtable event, staff at Rogosin have been working to develop and implement the defined projects. Building on the interviews conducted prior to the roundtable, a patient-engagement committee at Rogosin is developing a questionnaire to survey patients across units about their needs and healthcare experiences. In December, Dr. Philip Muskin, psychiatrist and Roundtable participant, trained Rogosin staff in the coherent breathing method, which can be used to calm both staff and patients. Discussions are in process to pilot art therapy sessions with patients at Rogosin dialysis units. Additionally, Rogosin is currently bringing iPads to dialysis units for patient use during treatment, and staff members are researching entertaining and therapeutic apps to help improve patients' experiences during treatment. Leadership at Rogosin is also pursuing additional training opportunities and support for staff to be able to address anxiety and depression among our patients.

While we believe that we are taking steps in the right direction at Rogosin to better address the needs of our ESRD patients, including their mental and emotional health needs, we recognize that this is an ongoing process, and that there is no quick fix. We must continue to build partnerships and to provide more comprehensive



support structures for patients navigating such a complex health system if we expect to see improved health outcomes. We welcome additional ideas and opportunities to collaborate to improve health and quality of life of the patients we serve, and are particularly eager to create an environment where patients and providers work together as partners in improving care. ■

Special thanks to DPC Education Center Board Members Mike Guffey and Diane Brisbane for participating in this important roundtable discussion and sharing their patient perspectives.



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.

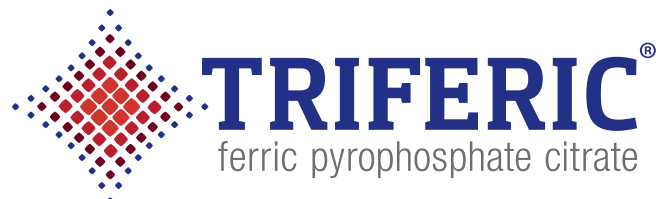
Triferic is the only drug FDA approved to replace iron at every hemodialysis treatment and to maintain hemoglobin concentration.

- 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)

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



Visit www.triferic.com



TO MEDICARE OR NOT TO MEDICARE: THAT IS THE QUESTION.

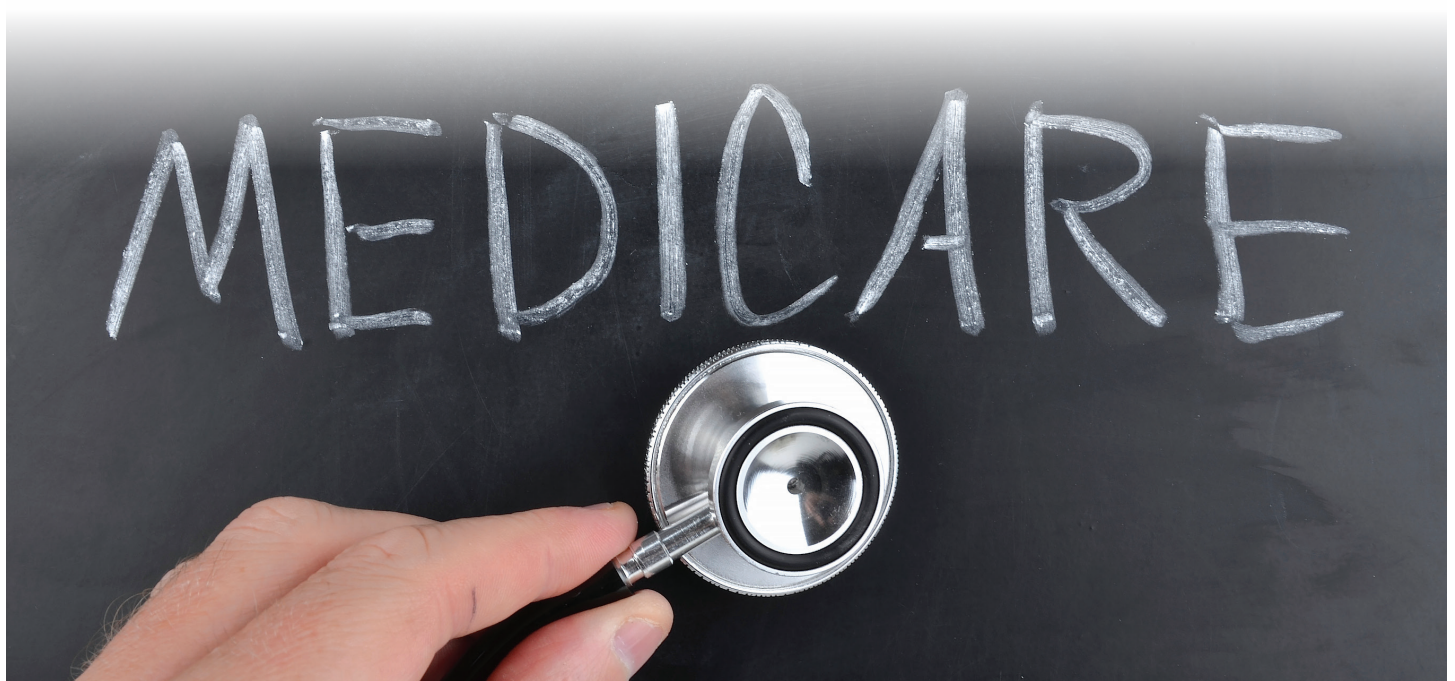
By **Kristen Seddon**

Fresenius Medical Care Financial Coordinator

Understanding insurance options can be very confusing. Where you live, where you have worked, currently work or may work are just a few factors to consider. In truth, when you are on dialysis, there is no universal option that will assist everyone in any situation. The insurance that may work for the dialysis person sitting next to you, your spouse or your best friend, may be the best or worst option for you. The focus of this article will be the most common insurance option, Medicare. It will cover the risks and benefits of choosing that coverage. **Medicare** is the most common



insurance option for dialysis patients. Here, I will briefly review some of the risks and benefits of choosing that coverage. **Medicare Part A** is hospitalization insurance. Typically, it is at no cost to you (as most of us pay into the Medicare system through years of employment). **Medicare Part B** averages \$121.80 per month and covers outpatient services. Examples of this are your family doctor, outpatient physical and occupational therapy and, of course, dialysis. Medicare is an option that most people consider when they turn 65. However, in the “land of Dialysis”, many people are able to obtain Medicare, regardless of their



age as long as they qualify for it by having enough work credits.

For individuals who are already Medicare beneficiaries when diagnosed with ESRD, coverage begins immediately. For those who are under 65 years of age and on dialysis may become entitled to Medicare upon meeting certain conditions:

- The first month of starting dialysis as long as you have participated in and completed home dialysis training.
- The 4th month from when they start dialysis if you are undergoing hemodialysis in a dialysis clinic.
- How to know “Is Medicare is right for Me?”

The main thing to figure out if you obtain Medicare is: how will it affect your current insurance? If you have an Affordable Care Act (ACA) or exchange plan, adding Medicare may cause you to lose the subsidy or possibly the entire plan itself. If you have COBRA coverage (group insurance after employment), you may lose the COBRA policy when Medicare becomes effective. If you have insurance through



on average, the total cost for Medicare over a year is \$1,461.60. If your total out of pocket and deductibles are less than \$1,461.60, getting Medicare may not be in your best financial interest. If your deductible and out of pocket costs are more than \$1,461.60, then the

Medicare benefit can save you money. It is important to note that Medicare will cover 80% of healthcare expenses. Without supplemental insurance, your total cost will be the premium price plus the remaining 20%. There also comes a point (30 to 33 months from the time you start dialysis which is also referred to as the Coordination of Benefit period) where you have to pick up Medicare or risk being financially penalized when you enroll in it later. Again, some people will not have to take the Medicare option --but most will need it.

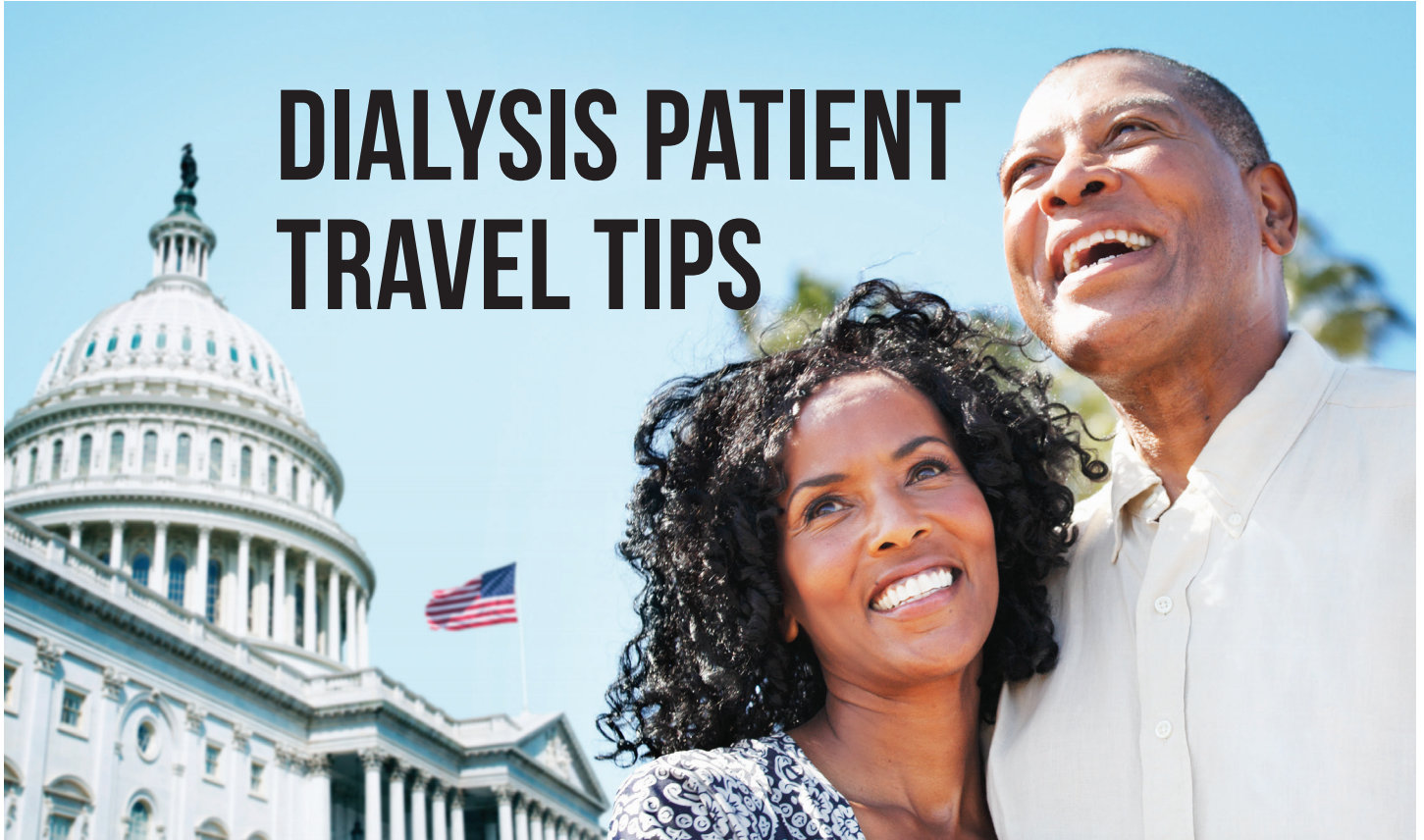


full time employment, Medicare can assist with the out of pocket and deductible expenses of your employer insurance plan

If you are working full time, you may want to consider getting Medicare. But, first, figure out if it is cost-effective. Since Medicare Part B costs \$121.80 per month,

Typically, all dialysis facilities have Social Workers and many patients receive visits from the Financial Coordinators or Insurance Counselors. These people can be very helpful when looking at the Medicare option. There are so many rules and factors to look into when considering Medicare that having someone who has a clear picture of your insurance situation can be a great help. The local Social Security office or state service center also can be a good resource for understanding the Medicare benefit. No matter what, before you sign up for benefits be sure you understand the risks and benefits of doing so.

DIALYSIS PATIENT TRAVEL TIPS



By **Joanne Smith**

Education Manager, DPC Education Center

Patients who receive dialysis can travel without missing their treatments while away from home. Of course, you should always consult your doctor before planning to travel. Most doctors encourage travel if the patient is assessed as being relatively healthy. Traveling can give a big boost to a patient's morale and sense of well-being and prevent depression and alienation from friends and family members.

Planning for hemodialysis treatments when away from home:

Dialysis centers have staff members who are experienced in arranging dialysis treatments when patients are traveling. Some centers will assist patients in making their own arrangements. Ask your social worker or another member of your health care team with whom you should discuss your plans.

There are also dialysis cruise options available that provide hemodialysis treatments or support your home dialysis treatments. Each cruise has a board certified nephrologist, dialysis RNs, and a number of dialysis technicians depending on how many patients need dialysis while cruising. The treatment cost

is usually a flat rate depending on the length of the cruise. Unfortunately, Medicare and Medicaid will not cover the dialysis cost onboard any cruises, however there are many supplemental insurance companies that will reimburse a percentage. You can receive an itemized statement of your treatments so you can file a claim.

Start planning your trip as soon as you know the details, at least six to eight weeks in advance. It may be difficult to reserve a dialysis chair in a popular vacation spot or during holidays. Be flexible about the dates for your trip as space in dialysis units may be limited. If you would prefer to have your treatments on specific days and at specific times, let the center know in advance. The unit will usually make every attempt to honor your request.

You or your Patient Travel Coordinator may need to contact more than one center in order to find a center that can provide dialysis for you. Larger dialysis companies usually will give you several options if they are available. Check with the center as soon as you arrive to confirm your appointment dates and times. You may also want to visit the center and meet the staff so you will feel more comfortable and to complete the admission paperwork.



Last minute plans that need to include dialysis

Many dialysis centers make every effort to accommodate patients in the event of an emergency such as illness or death of a family member. Dialysis records can be faxed ahead, or you can hand carry them with you.

Required information for a dialysis facility

Your demographics: Name, address, phone number, emergency contacts, insurance

- Medical history and recent physical exam reports
- Recent lab results
- Recent EKG
- Recent chest x-ray
- Your dialysis orders and 3 to 5 recent treatment records to review trends of your treatments
- Dialysis access type and location - i.e., right upper arm fistula (RUAF), CVC or graft
- Special needs or dialysis requirements
- Information about your general health
- Where you will be staying in the area with contact names and phone numbers
- A list of the medications you take during treatment and at home

The medical director or clinical manager will review your records and communicate with your home facility with any questions to insure a smooth transition. In addition, you should hand carry a copy of your records with you.

Questions you may want to ask before visiting the facility you will be traveling to:

- Does the center reuse dialyzers?
- What are the hours and days of operation? Traveling patients often are placed on an evening shift, which could

end as early as 7:30 p.m. or as late as 2:00 a.m.

- Can you use the same type of dialyzer you use at your home center?
- Are there individual televisions for each patient?
- Are there visitor restrictions?
- Will you be seen by a Nurse Practitioner or Physician during your visit?
- Are patients permitted to eat or drink while on dialysis?
- Is an ice machine available for patients?
- Is public transportation available to get to the center?
- How many patients are assigned to each nurse or patient care technician?
- Can you get all the medications you get at your home center during dialysis?
- What is the referring hospital for emergencies?

How to prevent getting sick during your time away

Don't overschedule activities beyond your normal level. Allow enough time to enjoy sightseeing outings and activities without becoming overtired. Also, be sure to watch your diet and fluid intake. Before you begin your trip, you will most likely have a doctor assigned to you by your transient dialysis center. Find out how to contact the doctor when you first arrive. If you do become ill, call the dialysis center or doctor as instructed.

It is possible that a transient patient may require hospitalization. If this should happen to you, your transient doctor is prepared for this possibility and will care for you during your hospital stay. He or she will probably talk to your regular doctor to coordinate your care. You may feel more comfortable to know if this coordination has taken place. Being hospitalized while away from home can be a stressful experience for any patient, and it certainly can change your travel plans. Preparing ahead for this possibility can help make the experience less stressful. The following suggestions may be helpful:

- Make sure your family knows your travel plans.
- Make sure you have important phone numbers with such names as your regular doctor, dialysis center, etc. Have a copy of your medical records with you while traveling.
- Make sure anyone who is traveling with you knows where you keep your records and what your medical needs are.
- Make sure to bring enough of the medications you need to take to last for the entire trip, with enough extra to deal with possible emergencies such as lost luggage or a spill. Also carry written prescriptions just in case.■



Home hemodialysis away from home

Some home hemodialysis patients make arrangements for in-center treatments while traveling to avoid having to pack up their machine. Some patients travel with their machines and equipment and simply perform their treatments at their convenience as they do at home.

Even if you do your own treatment, it is important to know where the closest dialysis center is where you could go for assistance. Let the center know when you will be in the area, and ask if they would be willing to provide medical assistance if needed. Carry complete medical information with you. Remember that most dialysis and equipment companies have toll-free numbers for assistance 24 hours a day. Carry these numbers with you.

Peritoneal dialysis away from home

Traveling is often easier for peritoneal dialysis patients because they are not dependent on the availability of a dialysis unit. Peritoneal dialysis patients still need to plan ahead and arrange for back-up medical care for their trips, as do hemodialysis patients. Typically, this would mean contacting a dialysis center in the area that provides home dialysis services and asking for the on-call, after hours number should a problem arise. The center may request a copy of your medical records in advance. In any case, you should always carry a copy of your records with you as well.

PD patients should carry enough supplies for the length of the trip, plus some extra supplies in case of problems. It is possible to arrange for delivery of supplies to your destination for longer stays. Make sure these supplies have arrived before you leave on your trip. PD patients also need to plan for adequate clean space where they may do their exchanges while traveling.

Traveling if you are active on a transplant waiting list

You should inform your transplant coordinator about your travel plans. The coordinator will help you decide whether to be “on hold” during the trip or whether you would be able to return within a reasonable amount of time if a kidney becomes available. Arrange to be contacted in the event a kidney becomes available.

Insurance during travel

If Medicare is your primary insurance coverage, Medicare will pay for 80 percent of your treatment costs within the U.S. and its territories. You will be responsible for the remaining 20 percent not covered by Medicare. If you have secondary insurance, it may cover this 20 percent. Check with the transient center about their policy on this. Most state Medicaid programs will not pay for treatment outside of your home state.

If you have commercial insurance as your primary insurance, you may need to request a letter from your insurance company stating they will pay for your treatment at the destination dialysis center. Some commercial insurance will pay for dialysis outside of the U.S. Transient dialysis centers will often call and verify this coverage themselves. Be sure to allow enough planning time to make these arrangements.

A doctor’s fee may also be charged by the transient dialysis center. Be sure to ask what portion of this charge will be your responsibility.

Don’t forget:

ALWAYS HAND CARRY ALL MEDICATIONS AND IMPORTANT HEALTH DOCUMENTATION WITH YOU.

PROTEIN AND DIALYSIS

By **Shadi Fattah**, RD, LDN, Registered Dietitian

Eating a high protein diet is very important in general, but even more so for people on dialysis. Protein plays a major role in growth and repair of body tissues, wound healing, fighting infections, muscle growth and fluid management.

Protein also plays an important role in dialysis treatments. Albumin is a protein found in the liver and is used to measure protein levels in the blood. People with low albumin generally also have muscle loss, weight loss, hair loss, fatigue, higher chance of infections, body swelling (edema), longer hospital stays and increased risk of heart disease.

Dialysis patients lose amino acids (building blocks for protein) with hemodialysis and protein with peritoneal dialysis. Patients on peritoneal dialysis need a bit more protein to maintain adequate protein levels. Up to 7 grams of protein is lost each day during peritoneal dialysis.

7 GRAMS OF PROTEIN IS EQUIVALENT TO

- 1 large egg
- 1 oz of meat
- 1/2 protein bar
- 1/4 cup of cottage cheese
- 3 pieces of medium size shrimp
- 1/2 cup of chickpeas

Patients undergoing hemodialysis should eat 1.2 g/kg of protein every day, while peritoneal dialysis patients should aim for 1.3g/kg (grams of protein per kg of body weight). A 150 lbs (68kg) person on peritoneal dialysis then needs approximately 89 grams of protein each day. Most patients need between 80-100 grams (10-12 oz) of protein each day. Best sources of protein include eggs, chicken, beef, turkey, pork, tuna, fish, beans and some dairy products such as cottage cheese and Greek yogurt. Always check with your renal dietitian before introducing beans and dairy products into your diet due to their high phosphorus and potassium contents.



HOW TO GET AT LEAST 80 GRAMS OF PROTEIN

Breakfast

- 2 eggs
- 1/2 cup milk
- 1/2 cup of berries

Lunch

- Tuna sandwich (1/2 cup of tuna)
- Or roast beef sandwich

Snack

- Small protein bar or 1/2 cup cottage cheese
- Or 1 small Greek yogurt

Dinner

- 3 oz of chicken
- 1/2 cup of green beans
- 1 small roll

Many people on dialysis need to add a protein supplement to their diet to increase protein intake. This can include ready to drink protein shakes, protein bars, protein powders and protein shots. Always check with your renal dietitian before starting a protein supplement.

Make sure you are getting adequate protein from your diet. Remember to always eat your protein first (before starch and veggies) since it's the most important part of your meal. Work with your dietitian on ways to increase your protein intake. To lead a long and healthy life, you need to eat a high protein diet.



High Protein Recipes

Garlic Chicken

Yield: **Serves 6 (Serving size 3 ounces)**

Ingredients

- 1 pound chicken breasts, boneless, skinless cut into 1/2-inch chunks
- 1/2 c. green peppers, diced
- 1/2 c. green onions (scallions), chopped
- 1/4 c. olive oil
- 8 cloves garlic, chopped
- ground black pepper to taste
- Mrs. Dash® (optional) – be careful with this if you are potassium-restricted

Directions

1. In large bowl, combine chicken, green peppers, and scallions.
2. Add olive oil, garlic, pepper, and Mrs. Dash, if using. Mix with wooden spoon, cover, and refrigerate overnight.
3. The following day, when ready to cook, sauté chicken mixture in large skillet or wok. Cook on low heat until chicken is cooked through.

Note: May be served over rice if desired.

Each Serving Contains:

- Calories: 177
- Protein: 17 g
- Carbohydrate: 3 g
- Total Fat: 11 g
- Potassium: 340 mg
- Phosphorus: 170 mg
- Sodium: 90 mg

CONTRIBUTED BY: CHERYL LEWIS, REGISTERED DIETITIAN, FRESenius MEDICAL CARE WILKES-BARRE, PENNSYLVANIA

Petite Meatballs

Yield: **28 meatballs; 7 meatballs = 1 serving**

Ingredients

- 1 lb. extra lean ground beef
- ½ cup soft bread crumbs
- 1/3 cup 1% milk (5 tablespoons)
- ½ teaspoon onion powder
- ¼ teaspoon garlic powder
- 1/8 teaspoon pepper
- 1 tablespoon olive oil or canola oil



Directions

1. Combine ground beef, bread crumbs, milk and seasonings; mix lightly.
2. Shape mixture to form 1-inch balls.
3. Brown meat balls in oil.
4. Cook 2 minutes, stirring frequently.
5. Serve with hot horseradish sauce or mustard sauce.

Per Serving contains:

- Calories: 318
- Protein: 21 g
- Phosphorus: 182 mg
- Potassium: 336 mg
- Carbohydrate: 4 g
- Total Fat: 23 g

Contributed by:

The Council on Renal Nutrition of New England (CRNNE)
Originally published in "Now You're Cooking...A Resource for People with Kidney Disease."

Recipes for Protein Shakes/Drinks

Cream of Wheat with Protein

- 1 Packet Instant Cream of Wheat
- 2/3 cup water
- 1 scoop of vanilla protein powder

Vanilla Smoothie

- 1 cup water
- 1 scoop or packet Vanilla protein powder
- 1/4 cup Frozen Fruit (Examples: 3 small Strawberries, 3 peach slices, ¼ cup blueberries, or ¼ cup raspberries)

Note: If you use fresh fruit, add ¼ cup ice.

Protein Coffee

- 8 oz cup of coffee (allow it to cool)
- 1 scoop of vanilla or plain protein powder

Protein lemonade

- 1 scoop of berry protein powder
- 8-16 oz of sugar free lemonade

Root beer Float

- 1 cup of flat A & W root beer
- 1 scoop of vanilla protein powder

Almond milk protein shake

- 8 oz of almond milk
- 1 scoop of vanilla protein powder

Applesauce with Protein

- 1 container of sugar free applesauce
- 1 scoop of unflavored protein powder



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