

ESRD Patient News

Summer Time and the Living is Easy

There are ways to make it easier living in the summer for dialysis patients. The food is plentiful, vacations are calling and you can enjoy it with a little planning. Enjoy this edition of **ESRD Patient News**.

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Diabetes Medicine, Dialysis Patients, and Heat

It's summer and you want to stay safe in the heat. This also includes keeping your medications safe. Extreme temperatures can damage medications and diabetes-related equipment if left out in the heat for a long period of time.

Here are some ideas to help protect medications while out in the sun:

- ⇒ Avoid placing insulin or diabetes equipment in direct sunlight or in a hot vehicle. Heat may cause damage or change the way the medication or devices work.
- ⇒ While traveling or working outdoors, keep insulin and other medications in a cooler. Do not put insulin directly on ice or on a gel pack, because it may get damaged.

Check in with your health care team to address any questions about your current medication routine and how heat may affect their diabetes.

Additionally, for all dialysis patients, the heat can result in a hospital stay. This is in part because of fluid restrictions and can also be related to sometimes needing to rest after dialysis.

Some tips to help reduce the likelihood of a hospital stay follow.

Never sit in your car. Dialysis patients are more susceptible and at higher risk for heat-related illness than the general population.

Try to avoid doing strenuous activity in the warm weather. Instead engage in in-home activities like walking around the house or riding a stationary bike.

Stay cool. Use the air conditioning. Also, a sponge bath with a cool sponge or a cold shower can bring relief.

Fluid limits. Remember that there are certain foods that will increase thirst. Avoid them as much as possible—things like chips, sports drink, etc. Try sucking on ice chips and eating frozen grapes.

Know the warning signs of heat exhaustion and heat stroke. These include vomiting, weakness, dizziness, and fainting for heat exhaustion.

If you also experience high behavior and confusion, call 911. This could be a heat stroke.



ESRD Patient News—a publication of The Carlisle-Williams Foundation, Inc.—informs our readers of issues important to management and understanding of their disease and to further the Foundation's mission of providing hope and support to ESRD patients. We welcome and encourage feedback through email (JanieC@esrd-patient-support.org) or by using the "Contact Us" form on the website. Thank you!

Eating Tips while Traveling on Dialysis

When you travel, it's important to eat kidney-friendly foods to help you enjoy your trip. These kidney diet travel tips are taken from a Davita article.

Use your resources

Tell your dietitian where you're traveling and what foods you expect to be available. It will help to understand your options and make a travel diet plan.

Always read nutrition labels. Avoid foods high in potassium, phosphorus and dairy. Also, check labels for sodium content.

Ask for a nutrition guide at fast-food restaurants or you can purchase a new or used nutrition guide online. These guides can help you make the smartest choice for your kidneys.

Look for nutritional drinks made for people with kidney disease. They can be used as meal replacements or supplements if you are not eating enough.

Remember the basics

Include a good protein source with each meal, along with fruits, vegetables and salads. Choose bagels, dinner rolls or English muffins. Keep portions moderate.

Avoid breading, sauces, bis-

cuits and dairy. If only high-sodium foods are available, limit sodium at your other meals. Remember that salty foods can cause you to drink more.

Drink water instead of soda. Try sparkling or seltzer water flavored with lime, lemon or many other different flavors. You get the sensation of drinking soda without the sugar, potassium or phosphate.

For diabetics, try to limit sweets and sugary drinks (including juices), and be careful with salty foods and condiments. Check your blood sugar daily to help stay on track.

If you're taking phosphate binders, remember to pack plenty and keep them with you.

Road trips and camping

Use a cooler to keep foods fresh and handy, and make fast food less tempting.

Pack fresh-cooked meats, unsalted canned tuna or chicken, or low-sodium deli meats. Try unsalted pretzels or low-sodium crackers. For dessert, have a piece of low-potassium fruit or low-sodium cookies.

Avoid chips and packaged/processed meats, as they can be high in sodium and phosphorus.

Pack well, wash your hands and use hand sanitizer.

Cruises

When booking your cruise, tell them your dietary needs. Many cruise lines will prepare foods for special needs. Low-sodium meals may be available.

Stick to reasonable portions and regular mealtimes, despite the availability of buffets around the clock.

Amusement parks

Pack a kidney-friendly lunch in a cooler and eat in the park's picnic area or eat at your car.

If eating in the park, order hamburgers (no cheese) or skinless chicken.

Avoid hot dogs, breaded chicken or fish as well as French fries or potato wedges (high in potassium).

Travel abroad

Learn about the foods typical at your destination. Then, ask your dietitian to help you make a list of foods to eat (and avoid) in that country.

If you don't speak the language, bring a phrase book with a food-ordering section.

<https://www.davita.com/services/article.cfm?servicesMainFolder=travel-support&category=travel-tips-and-articles&articleTitle=eating-tips-for-travelers-with-kidney-disease>

Disease Education-Diabetes Insipidus

What is diabetes insipidus?

Diabetes insipidus (DI) is a rare disease that causes frequent urination. The large volume of urine is diluted, mostly water. To make up for lost water, a person with DI may feel the need to drink large amounts and is likely to urinate frequently, even at night, which can disrupt sleep and, on occasion, cause bed-wetting. Because of the excretion of abnormally large volumes of dilute urine, people with DI may quickly become dehydrated if they do not drink enough water. Children with DI may be irritable or listless and may have fever, vomiting, or diarrhea. Milder forms of DI can be managed by drinking enough water, usually between 2 and 2.5 liters a day. DI severe enough to endanger a person's health is rare.

What is the difference between diabetes insipidus and diabetes mellitus?

DI should not be confused with diabetes mellitus (DM), which results from insulin deficiency or resistance leading to high blood glucose, also called blood sugar. DI and DM are unrelated, although they can have similar signs and symptoms, like excessive thirst and excessive urination.

DM is far more common than DI and receives more news coverage. DM has two main forms, type 1 diabetes and type 2 diabetes. DI is a different form of illness altogether.

How is fluid in the body normally regulated?

The body has a complex system for balancing the volume and composition of body fluids. The kidneys remove extra body fluids from the bloodstream. These fluids are stored in the bladder as urine. If the fluid regulation system is working properly, the kidneys make less urine to conserve fluid when water intake is decreased or water is lost, for example, through sweating or diarrhea. The kidneys also make less urine at night when the body's metabolic processes are slower.

To keep the volume and composition of body fluids balanced, the rate of fluid intake is governed by thirst, and the rate of excretion is governed by the production of antidiuretic hormone (ADH), also called vasopressin. This hormone is made in the hypothalamus, a small gland located in the brain. ADH is stored in the nearby pituitary gland and released into the bloodstream when necessary.

When ADH reaches the kidneys, it directs them to concentrate the urine by reabsorbing some of the filtered water to the bloodstream and therefore make less urine. DI occurs when this precise system for regulating the kidneys' handling of fluids is disrupted.

How is diabetes insipidus diagnosed?

Because DM is more common and because DM and DI have similar symptoms, a health care provider may suspect that a patient with DI has DM. But testing should make the diagnosis clear.

A doctor must determine which type of DI is involved before proper treatment can begin. Diagnosis is based on a series of tests, including urinalysis and a fluid deprivation test.

Urinalysis is the physical and chemical examination of urine. The urine of a person with DI will be less concentrated. Therefore, the salt and waste concentrations are low and the amount of water excreted is high. A physician evaluates the concentration of urine by measuring how many particles are in a kilogram of water or by comparing the weight of the urine with an equal volume of distilled water.

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Elevated Protein Level Increases Risk of Kidney Disease

The Carlisle-Williams Foundation Inc. is a 501(c)(3) nonprofit charity. Consider making a tax-deductible donation to help us in our mission to reduce hospital stays and increase approval for kidney transplant, by improving dialysis patients' compliance with treatment.

(HealthDay News) Black Americans with gene variants that raise their risk of chronic kidney disease (CKD) don't always develop it, and researchers now think they know why.

Fifteen to 20 percent of black Americans have inherited variations of the apolipoprotein L1 putting them at risk for chronic kidney disease. Only about half are diagnosed with the illness.

Scientists analyzed blood samples from more than 1,000 black Americans who had the genetic risk. They found that elevated levels of a protein called suPAR triggered the start and progression of CKD in those with the gene variants.

"What we are learning today is that suPAR is to kidneys what cholesterol is to the heart, a substance that can cause damage if levels rise too high, or a substance that can likely make many forms of kidney disease worse," said senior study author Dr. Jochen Reiser, chair of the internal medicine department at Rush University Medical Center in Chicago.

Everybody has suPAR, which is produced by bone marrow cells, in their blood. As levels of suPAR rise, the risk for kidney disease rises.

Reiser said the results of the study could lead to new treatments for CKD that target these risk factors.

Factors such as smoking, weight gain and frequent infections can boost suPAR levels, so people with this genetic risk for kidney disease should try to follow good health habits, the researchers added.

"Lifestyle is a big factor, bigger than we thought," Reiser said in a news release. She concluded, "Based on these fundamental insights, suPAR level testing may become a routine test at many institutions around the world."

SOURCE: Rush University Medical Center, news release, June 26, 2017https://medlineplus.gov/news/fullstory_166903.html

Kidney-friendly foods—Some Basics

A kidney-friendly diet is one in which protein, phosphorus, and sodium levels are controlled. While the body needs protein for muscle growth and tissue repair, people with kidney disease cannot rid their bodies of the waste created when the body uses protein. Therefore, in order to limit waste build up, a kidney diet may control the amount of

protein consumed. In addition, phosphorus will need to be controlled to avoid losing calcium and weakening the bones. Sodium may need to be controlled to avoid high blood pressure. A kidney diet may also be higher in fats and carbohydrates than a normal diet.

A kidney diet may also be higher in fats and carbohydrates than a normal diet to

make up for not getting as many calories from protein. Kidney-friendly, high calorie foods include unsaturated fats such as vegetable oils, sugar and sweets such as candy and jelly, and canned fruit in heavy syrup. However, if you are also a diabetic, sugar must be limited.

Thyroid Problems May Make Things Worse for Dialysis Patients

(HealthDay News) Poor thyroid function may diminish kidney dialysis patients' health and quality of life, a new study suggests.

Hypothyroidism, a condition in which the thyroid gland does not produce enough thyroid hormone, is common in dialysis patients. How it affects them has been unclear.

450 dialysis patients who completed questionnaires every six months and had their thyroid function assessed were included in this study.

Poor thyroid function was asso-

ciated with poorer health-related quality of life, including low energy, increased fatigue, reduced physical function and greater pain.

"Given the high prevalence of thyroid dysfunction and low levels of quality of life in dialysis patients, future research is needed to determine the underlying mechanisms of these associations, and whether thyroid hormone replacement can improve the health-related quality of life of this population," said study author Dr. Connie Rhee, University of California, Irvine.

The study was published online July 13 in the *Clinical Journal of the American Society of Nephrology*.

"In addition, as the first study in dialysis patients to document an association between [thyroid problems] and low levels of physical function, a strong predictor of death, future studies are needed to determine whether correction of thyroid status ... can improve physical function in this population," Rhee concluded.

SOURCE: Clinical Journal of the American Society of Nephrology, news release, July 13, 2017

Diabetes Blamed for the Rising Rates of 2 Nerve Conditions

(HealthDay News) Two particular types of nerve damage have been increasing as more and more people develop diabetes in the United States.

Autonomic and small fiber neuropathy were once rare conditions. Both occur when small blood vessels supplying the nerves are damaged by diabetes because they don't get enough oxygen and nutrients, said Dr. Divpreet Kaur, neurologist at Penn State Health Milton S. Hershey Medical Center.

Diabetes is one main cause of neuropathy, and about 30 million Americans currently have diabetes, Kaur said. More commonly, people with diabetes have nerve damage that causes numbness in the feet and toes or peripheral neuropathy.

Autonomic neuropathy affects involuntary bodily functions such as blood pres-

sure, digestion, urination, temp control and sweat regulation.

"The most common symptom is lightheadedness, especially when standing up. The blood pressure drops so much when they stand up that they feel like they are going to pass out," Kaur said.

People with small fiber neuropathy often have burning pain in their feet that eventually progresses up their legs. The hands can also be affected.

"People don't know about it or recognize the symptoms, and they keep going to different physicians without receiving a diagnosis. It isn't that every patient who has these symptoms will definitely have such a neuropathy. Once common things have been ruled out by their primary care physician, they can be referred to the neuromuscular clinic for consultation or

to the autonomic laboratory for further testing," she said.

There is no cure for either form of neuropathy, and treatment varies depending on the part of the body affected and the symptoms, Kaur said.

Treatment for small fiber neuropathy often involves controlling pain. For autonomic neuropathy, medications can be used to help regulate malfunctioning bodily functions, she said.

Progression of neuropathy associated with diabetes or other underlying conditions can be stabilized or slowed by controlling and treating those conditions. However, an underlying condition can't be identified in nearly one-third of neuropathy patients, the researchers said.

SOURCE: Penn State Health, news release, July 12, 2017

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Donor Kidneys Rejected by Centers 7 Times on Average

(HealthDay News) A donated kidney is turned away for transplant an average of seven times before reaching the patient who finally receives it, a new study shows.

Transplant centers regularly reject kidneys based on a donor's age or perceived quality of the organ, even though the kidneys are eventually accepted and work well for people farther down the waiting list, explained lead researcher Dr. Anne Huml, a nephrologist and health disparities fellow with Case Western Reserve University in Cleveland.

The centers are likely being appropriately picky in selecting organs to ensure the greatest chance of success by carefully matching each kidney to each recipient, Huml said. "If someone's been waiting five years, why rush and take the first kidney offered when within a month they'll be offered a better kidney and their outcome will be better?" Huml said.

Such hesitation can mean that patients high on the waiting list remain on dialysis while organs that would

have suited them pass down to others who've waited less time, said Dr. Sumit Mohan, associate professor for medicine and epidemiology at Columbia University's Mailman School of Public Health.

"The general sense is that surgeons are less willing to take risks, so what ends up happening is there are a large number of kidneys that people say no to that end up getting transplanted way down the list," said Mohan.

Patients rarely are told that their transplant center has passed on a donor kidney offered to them. "If your surgeon says no, I don't want that kidney, you're never informed. You're not even told that's the case," Mohan said. "Patients need to be more engaged in the process and have a better understanding of what's being agreed to on their behalf."

More than 100,000 people currently are waiting for a kidney transplant in the United States, Mohan said.

Despite this, nearly 1 in 5 deceased donor kidneys are discarded annually. Nearly 15% of organs are tossed

away because no recipient can be located, Mohan said.

Dialysis keeps a delay in receiving a kidney from becoming immediately life-threatening, Huml said. However, there is a high mortality rate associated with dialysis, and people who are on dialysis longer don't do as well once they have received a kidney, Mohan said.

For the study, Huml and her colleagues reviewed more than 7 million organ offers that were made for 31,230 kidneys from deceased donors between 2007-2012. All the kidneys were eventually transplanted.

The researchers found that donor kidneys were offered a median of seven times to different patients before being accepted for transplantation.

Transplant centers largely pass on kidneys from donors with high blood pressure, a history of diabetes, reduced kidney function or death related to heart problems.

In those cases, centers that want to keep their success rates high are rejecting or-

Donor Kidneys Rejected by Centers 7 Times on Average

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gans that appear dicey, even though they end up being successfully transplanted into another patient, Mohan said.

The study also found that transplant centers are pickier in choosing kidneys for patients who are male, Hispanic, overweight or obese, or suffering from high blood pressure resulting from kidney failure, Huml said.

Patients with medical problems such as excess weight or high blood pressure likely face more difficult surgeries, and doctors are choosier about the kidney that's right for them, Mohan explained.

"Those are much harder patients to operate on, and the risk of complications is higher," he said.

The longer waits for men and Hispanics also could be related to these medical problems, Mohan added. For example, men needing kidney transplants might be more likely to have high blood pressure or be obese than female counterparts.

Centers are trying to maximize the effect of transplantation by

steering organs to the right people, said Dr. David Klassen, chief medical officer for the United Network for Organ Sharing, the private non-profit that manages the nation's organ transplant system.

For example, it makes little sense to transplant a very healthy kidney expected to work for 40 years into a 70-year-old person with a life expectancy of 10 years, he said.

That said, changes made to the organ allocation system in 2014 have addressed some of the concerns raised by this study, Klassen said. The changes require that minorities receive a percentage of donated organs that reflects the percentage of waiting list patients they represent, Klassen said.

In addition, officials changed the way waiting time is calculated, Klassen said. Waiting time is now calculated from the time you were put on dialysis, to reflect the fact that dialysis is riskier for patients.

Mohan recommended two additional reforms to the system that could help get kidneys to appropriate patients more quickly:

Provide feedback to transplant centers on organs they reject that wind up being acceptable elsewhere. "I think we have an obligation to go back to the transplant center and say somebody else chose to use that kidney," he said. "You may want to rethink that clinical choice you made."

Give patients access to organ acceptance rates at transplant centers near them. "If I want to make an informed choice as a consumer, I want to know be able to look at how aggressive is a certain center, how willing are they to take certain kinds of organs, what is the wait time," Mohan said. "We need to provide that information to patients if they are going to make these choices."

SOURCES: Anne Huml, M.D., nephrologist and health disparities fellow, Case Western Reserve University, Cleveland; Sumit Mohan, M.D., MPH, associate professor, medicine and epidemiology, Columbia University Mailman School of Public Health, New York City; David Klassen, M.D., chief medical officer, United Network for Organ Sharing; July 27, 2017, Clinical Journal of the American Society of Nephrology

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Disease Education-Diabetes Insipidus

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A fluid deprivation test helps determine whether DI is caused by one of the following:

- excessive intake of fluid
- a defect in ADH production
- a defect in the kidneys' response to ADH

This test measures changes in body weight, urine output, and urine composition when fluids are withheld. Sometimes measuring blood levels of ADH during this test is also necessary.

In some patients, a magnetic resonance imaging (MRI) of the brain may be necessary as well.

Points to Remember

- Diabetes insipidus (DI) is a rare disease that causes frequent urination and excessive thirst.
- DI is not related to diabetes mellitus (DM).

- Central DI is caused by damage to the pituitary gland and is treated with a synthetic hormone called desmopressin, which prevents water excretion.

- Nephrogenic DI is caused by drugs or kidney disease and is treated with hydrochlorothiazide (HCTZ), indomethacin, or a combination of HCTZ amiloride.

- Scientists have not yet discovered an effective treatment for dipsogenic DI, which is caused by a defect in the thirst mechanism.

- Most forms of gestational DI can be treated with desmopressin.

- A doctor must determine which type of DI is involved before proper treatment can begin.

Taken from NIH Publication No. 08-4620

How can we help ?

Visit our website

www.esrd-patient-support.org



The Carlisle-Williams Foundation Inc.
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