

ESRD PATIENT NEWS

The Carlisle-Williams Foundation, Inc.

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Talking With Your Doctor-Make the Most of Your Appointment

Patients and health care providers share a very personal relationship. Doctors need to know a lot about you, family, and lifestyle to give you the best medical care. Speak up and share your concerns and questions. Clear and honest communication help you both make smart choices about your health.

Before your appointment, make a list of concerns and questions you have. Bring it to your appointment, so you won't forget anything.

"There's no such thing as a dumb question in the doctor's office," says Dr. Matthew Memoli, an infectious disease doctor. "I try very hard to make my patients feel comfortable asking questions, no matter how dumb they think the question is."

Even if the topic seems sensitive or embarrassing, be honest and upfront with your health care provider. Your doctor is used to talking about all kinds of personal matters.

Consider taking a family member or friend when you visit the doctor. They can help if there are language or cultural differences. If you feel unsure about a topic, the other person can help you describe your feelings or ask questions on your behalf. It also helps to have someone else's perspective. Your friend may think of additional questions concerns.

"As a physician, I personally have no problem with people looking on the Web for information, but they should use that information not as a way to self-diagnose or make decisions, but as a way to plan their visit with the doctor," says Memoli. Federal agencies are among the most reliable sources of

online health information.

Many health care providers now use electronic health records. Ask your doctor how to access your records, so you can track test results, diagnoses, treatment plans, and medicines.

If you have questions about any instructions or other concerns, call or email your health care provider. Don't wait until your next visit to make sure you understand your diagnosis, treatment plan, or anything else that might affect your health.

Your body is complicated and there's a lot to consider, so make sure you do everything you can to get the most out of your medical visits.

For the full article, visit <https://newsinhealth.nih.gov/special-issues/seniors/talking-your-doctor>

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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 furthers the Foundation's mission of providing hope and support to ESRD patients. We welcome and encourage feedback. Email JanieC@esrd-patient-support.org or "Contact Us" on the website. Thank you!

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Many Kidney Disease Researchers Aren't Focusing Enough on Patients, New Study Shows



We provide links to clinical research trials on our website. Check them often as new trials are constantly being added. It's a great opportunity to have a voice.

Many kidney disease researchers should consider dramatically increasing both their engagement of patients with kidney disease and the amount of their research that is focused on patient-centered outcomes, according to the authors of a study whose major findings will be presented at the National Kidney Foundation 2018 Spring Clinical Meetings in Austin, Texas.

The study, based on the results of an online survey of more than 1,500 individuals, including 657 kidney disease researchers, showed that nearly three-quarters of the researchers have never pursued patient-centered outcomes research.

The survey also revealed that almost one-half (46.8%) of the surveyed researchers publish only in academic journals, while failing to present results in venues more accessible to kidney disease patients. Of 860 patients and family members surveyed, nearly 9 out of every 10 (89.1%) expressed interest in being involved in such

studies but had not yet been involved in them.

“Getting patients engaged early in research will help insure the data, device, or drug is meaningful to patients and patients are willing use it,” said Teri Browne, Ph.D., a researcher at the College of Social Work at the University of South Carolina and lead author of the study.

Browne conducted the study in partnership with Derek Forfang, a kidney disease patient and a long-time kidney disease advocate.

Patient-centered outcomes research aims to help patients and their family members suggest research topics important to them, create research questions and outcomes in partnership with researchers, and fully participate in all aspects of research projects. It also involves patients and family members in the translation of the research findings to other patients, professionals, and communities.

In their study, Browne and the authors found that pa-

tients and care partners also specified that future research should prioritize studies which improve understanding of the biology of kidney disease and ways to prevent it. The most common barriers to patient engagement mentioned by researchers who were surveyed included difficulty doing research in dialysis centers, lack of funding for patient engagement within projects, and lack of knowledge of how to best engage with patients.

Barriers to research involvement cited by patients included travel limitations, lack of motivation, limited understanding of research, and lack of awareness of research opportunities. The study — which also includes authors from the non-profit organizations the National Forum of ESRD Networks and the National Kidney Foundation — has been accepted for publication in the American Journal of Kidney Diseases.

Teri Browne, Ph.D. <https://www.kidney.org/news/many-kidney-disease-researchers-aren%E2%80%99t-focusing-enough-patients-new-study-shows>

Common Food Safety Mistakes

Don't be one of the 48 million Americans sickened by food poisoning each year. Avoid these common, dangerous food safety mistakes.

Tasting food to see if it's still good

Never taste your food to check if it has spoiled. You can't taste, see or smell all bacteria that causes food poisoning. Tasting a tiny bit of contaminated food can cause serious illness. Throw away expired food before harmful bacteria grows.

Putting cooked or ready-to-eat food on a plate that held raw meat

Do not let raw meat, poultry or seafood touch cooked meat or ready-to-eat foods. This can cause cross-contamination. Foodborne pathogens from raw meat can easily spread to ready-to-eat foods and cause food poisoning. Always use separate plates, cutting boards and utensils to keep raw meats, poultry and seafood separate from ready-to-eat foods.

Thawing food on the counter

Don't thaw food on the counter. Harmful foodborne pathogens multiply rapidly when foods are in the danger zone between 40°F and 140°F. Thaw food in the refrigerator, cold water or in the microwave.

Letting food cool before putting it in the fridge

Don't leave food out of the refrigerator for more than two hours or one hour if it is over 90°F outside. Illness-causing bacteria grow rapidly when perishable foods are left in the danger zone - between 40°F and 140°F. Always refrigerate foods in a timely matter. On a road trip, tailgating or picnicking, pack perishable foods in a well-insulated cooler with ice or cold packs.

Eating raw cookie dough and other foods containing uncooked eggs and flour

Never eat any raw eggs because they may contain Salmonella or other harmful bacteria. Cook eggs thoroughly and avoid foods that contain undercooked or raw eggs. Even raw dough without eggs should not be consumed as raw flour may contain E. coli and cause people to get sick.

Marinating meat or seafood on the counter. Using raw meat marinade on cooked food.

Never marinate meat, poultry or seafood on the counter or use the same marinade for raw meat and cooked food. If you marinate on the counter, harmful germs can multiply rapidly when in the danger zone - between 40°F-140°F. If you use the same marinade

on raw and cooked meats, the harmful bacteria from raw food can spread to the cooked food. Always marinate raw meat, seafood and poultry in the refrigerator. Only reuse marinade if you bring it to a boil just before using.

Undercooking meat, poultry, seafood or eggs

Cooked food is safe only after it's heated to a high enough internal temperature to kill harmful bacteria. In order to avoid eating undercooked foods, use a food thermometer, the only way to determine if cooked foods are safe to eat.

Not washing your hands

Illness-causing bacteria can survive in many places, including your hands. Always wash your hands for at least 20 seconds with soap and warm, running water before and after handling food.

Not replacing sponges and dish rags

Sponges and dishrags are some of the dirtiest tools in your kitchen. They can hold harmful foodborne pathogens and cause a serious health risk. Sanitize sponges at least every other day and replace them every week or two for best protection against germs.

Reviewed by Taylor Wolfram, MS, RDN, LDN. Eat Right © 2018 eatright.org. Academy of Nutrition and Dietetics, All Rights Reserved.

Handling foods safely is much more than throwing away expired milk or washing your fruits and vegetables. While these actions are important, there are several more common food safety mistakes that can result in major consequences.

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Feeling Out of Joint-The Aches of Arthritis

What exactly is arthritis? “Arthr” means joint, and “itis” means inflammation - heat, swelling, and redness. But the inflammation of arthritis isn’t always something you can see.

Many people start to feel pain and stiffness in their joints as they get older, often around 45-50. It’s called arthritis, and is one of the most common diseases nationwide. Arthritis affects young adults and even children. In recent years, scientists have made rapid progress in understanding the many causes of arthritis, and significant strides in developing effective new treatments for the disease.

“Some types of arthritis are very inflammatory and others aren’t as much. But they all involve an element of inflammation,” explains Dr. Joanne M. Jordan of the University of North Carolina at Chapel Hill.

Arthritis comes in many forms-more than 100 types-each with its own symptoms and treatments. The most common form of arthritis is osteoarthritis.

Osteoarthritis occurs when cartilage breaks down and wears away. It most often affects fingers, knees, and hips. It can follow injury to a joint. Once you’ve had a severe joint injury, it’s

important to be careful about what kind of activities you do.

“You should be active because, ironically, being active can help prevent disease,” says Dr. David Felson of Boston University. “But try not to be active in ways that can make your joint vulnerable to injury again.”

It is uncertain how and why osteoarthritis occurs. Women tend to get it more often than men, and aging tends to be a factor.

“Many factors that affect osteoarthritis are things you can’t control, like how old you are and what gender you are,” Felson says.

But some risk factors are under your control, including your weight. “Even moderately overweight people have an increase in knee osteoarthritis,” says Felson.

Many treatments are available for osteoarthritis. Exercises can help and some activities should be avoided. Pain and anti-inflammatory medicines are available by prescription or over the counter.

Perhaps the most promising treatments for osteoarthritis, Felson says, involve ways to block pain. Researchers are working on other approaches, including exercise routines and devices that alter the alignment of your joints. For severe cases of osteoarthritis, scientists have developed improved surgeries to replace knees and hips.

Gout is a form of arthritis that usually affects the big toe, but many other joints may be involved. It’s caused by needle-like crystals that build up in the joints.

People with gout might try to avoid certain foods—including liver, beef, anchovies, and meat gravy—because they can bring on a gout attack in some people. These foods are rich in molecules called purines, which break down in your body and can ultimately contribute to crystal formation. Drinking alcohol, being overweight, and taking certain medications may make gout worse. In older people, some blood pressure medicines can also increase the

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chance of a gout attack. Your doctor might do blood tests and X-rays to find out if you have gout. If you are diagnosed with gout, it can be treated several different ways, often in combination.

A very different type of arthritis is called rheumatoid arthritis. In contrast to osteoarthritis and gout, which affect particular joints, rheumatoid arthritis can affect your whole body. It arises when your immune system mistakenly attacks your own joints, causing pain, swelling, stiffness, and loss of function in joints and bones, most often in the hands and feet. Rheumatoid arthritis may also affect your internal organs and systems. You might feel sick or tired or have a fever.

Laboratory tests for certain immune system activity can confirm whether you have rheumatoid arthritis. The good news is that now there are medications not only to control pain and inflammation, but to actually slow or stop damage to your joints.

Many new treatments that have come out in the past 10-15 years have revolutionized the treatment of rheumatoid arthritis,” Jordan says. Some rheumatoid arthritis medications interfere with the immune system’s activity, blocking inflammation and preventing structural damage to the joints.

“If you’re concerned you have rheumatoid arthritis, it’s important to see a doctor fairly soon,” Felson advises. “Your joints can be damaged by the process of arthritis, and that damage cannot be reversed, so it’s important to get treatment as early as possible.”

Researchers continue to explore what causes arthritis. A better understanding of the factors involved might lead to new treatment approaches. Genes play a significant role in many types of arthritis. Genes involved in how uric acid is processed have been tied to gout.

For osteoarthritis, Jordan estimates that up to 30% to 60% of your risk may lie in the genes you inherited from your parents. “The tricky

part, though, is that it’s not a single gene,” Jordan explains. “It’s a lot of different genes that interact with each other and with the environment to cause the disease.”

Researchers are also looking at other risk factors, such as job-related exposures and heavy metals, such as lead, in the environment. They’ve been developing better ways of looking inside joints as well.

If you feel pain and stiffness in your joints, don’t hesitate to bring it up with your doctor. The sooner you act, the better you can prevent damage to your joints. Find out what’s causing your problems now and learn about your options.

For the full article, visit <https://newsinhealth.nih.gov/special-issues/seniors/feeling-out-joint>

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Your Aging Eyes - How You See as Time Goes By

You may barely notice the changes at first. Maybe you've found yourself reaching more often for your glasses to see up close. You might have trouble adjusting to glaring lights or reading when the light is dim. You may even have put on blue socks thinking they were black. These are some of the normal changes to your eyes and vision as you age.

As more Americans head toward retirement and beyond, scientists expect the number of people with age-related eye problems to rise dramatically. You can't prevent all age-related changes to your eyes. But you can take steps to protect your vision and reduce your risk for serious eye disease in the future. Effective treatments are now available for many disorders that may lead to blindness or visual impairment. You can also learn how to make the most of the vision you have.

"Vision impairment and blindness are among the top five causes of disability in older adults," says Dr. Cynthia Owsley, an eye researcher at the University of Alabama at Birmingham. Vision changes can make it difficult to perform everyday activities, such as reading the mail, shopping, cooking, walking safely, and driving. "Losing your vision may not be life-threatening, but it certainly affects your quality of life," Owsley says.

The clear, curved lens at the front of your eye may be one of the first parts of your body to show signs of age. The lens bends to focus light and form images on the retina at the

back of your eye. This flexibility lets you see at different distances—up close or far away. But the lens hardens with age. The change may begin as early as your 20s, but it can come so gradually it may take decades to notice.

Eventually, age-related stiffening and clouding of the lens affects just about everyone. You may have trouble focusing on up-close objects, a condition called presbyopia. Anyone over age 35 is at risk for presbyopia.

"You might find you're holding your book farther away to read it. You might even start thinking your arms just aren't long enough," says Dr. Emily Chew, a clinical researcher at NIH's National Eye Institute. "A good and simple treatment for presbyopia is reading glasses."

Cloudy areas in the lens, called cataracts, are another common eye problem that comes with age. More than 24 million Americans have cataracts. By age 75, more than half of us will have had them. Some cataracts stay small and have little effect on eyesight, but others become large and interfere with vision. Symptoms include blurriness, diffi-

culty seeing well at night, lights that seem too bright and faded color vision. There are no specific steps to prevent cataracts, but tobacco use and exposure to sunlight raise your risk of developing them. Cataract surgery is a safe and common treatment that can restore good vision.

The passage of time can also weaken the tiny muscles that control your eye's pupil size. The pupil becomes smaller and less responsive to changes in light. That's why people in their 60s need three times more light for comfortable reading than those in their 20s. Smaller pupils make it more difficult to see at night.

Trouble seeing at night can affect many daily activities, including your ability to drive safely. Loss of peripheral vision increases your risk for automobile accidents, so you need to be more cautious when driving.

"Keeping older adults active and on the road as drivers, as long as they're safely able to do so, is considered important to their health and psychological well-being," says Owsley. But she notes that tests for motor vehicle licenses tend to focus on visual acuity—how

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well you can read the letters on an eye chart.

“Visual acuity tests may not be the best way to identify drivers at risk for crashes,” she says. “Other issues are also important, like contrast sensitivity, your peripheral vision and your visual processing speed—how quickly you can process visual information and make decisions behind the wheel.”

Owsley and her colleagues measured car crashes among a group of 2,000 drivers, 70 years old and older, over a period of three years. They found that a reduced field of vision and slowed processing speed both increased collision risk. Their research is helping to identify screening tests that can better predict safe or dangerous driving.

If you’re not convinced you should have regular eye exams, consider that some of the more serious age-related eye diseases—like glaucoma, age-related macular degeneration (AMD) and diabetic eye disease—may have no warning signs or symptoms in their early stages.

Glaucoma comes from damage to the optic nerve. “Glaucoma can slowly steal your peripheral vision. You

may not notice it until it’s advanced,” says Chew. It can be treated with prescription eye drops, lasers, or surgery. If not treated, however, it can lead to vision loss and blindness.

AMD causes gradual loss of vision in the center of your eyesight. “AMD is the leading cause of blindness in Americans over age 65,” says Chew.

A large NIH-supported clinical study by Chew and others found that a specific combination of vitamins and minerals can prevent AMD from progressing to a more severe form. Scientists also found that people who eat diets rich in green, leafy vegetables—such as kale and spinach—or fish are less likely to have advanced AMD. A large study of 4,000 AMD patients failed to show a benefit from fish oil supplements. However, vitamin/mineral supplements—especially those containing lutein and zeaxanthin, which are found in green leafy vegetables—slows progression to vision-threatening late AMD.

Diabetic eye disease, another leading cause of blindness, can damage the tiny blood vessels inside the retina. Keeping your blood sugar

under control can help prevent or slow the problem.

The only way to detect these serious eye diseases before they cause vision loss or blindness is through a comprehensive dilated eye exam. Your eye care professional will put drops in your eyes to enlarge, or dilate, the pupils and then look for signs of disease.

“Having regular comprehensive eye care gives your doctor a chance to identify a problem very early on and then treat it,” says Owsley. Annual eye exams are especially important if you have diabetes.

“Many of the healthy behaviors that help reduce your risk for long-term diseases, like heart disease and cancer, can also help to protect your eyesight,” says Owsley. These include not smoking, eating a healthy diet, and controlling conditions like diabetes and high blood pressure. “It’s nice to know that healthy living not only adds years to your life, but also protects your vision as you get older,”

Owsley says.

<https://newsinhealth.nih.gov/special-issues/seniors/your-aging-eyes>

“Don’t believe everything you think.”

Using a Home Test Kit and Smartphone to Test for Chronic Kidney Disease (CKD)

High blood pressure (HBP) is a contributing risk factor to CKD. One of the best ways to test for CKD and assess kidney damage is a urine test which detects the presence of albumin. The smartphone app from Healthy.io enables users to conduct a urinalysis test at home and securely share results with their clinicians.

Approximately 30 million Americans have CKD, but nearly 90% do not know they have this condition. Progression can be slowed or halted if the disease is caught in its early stages.

“Early detection of CKD is crucial so that risk factors can be aggressively managed to prevent end-stage renal disease and cardiovascular disease,” said Alexander Chang, M.D., practicing nephrologist and assistant professor in the Kidney Health Research Institute at Geisinger.

“This new trial using a smartphone app and urinalysis kit will provide important information on how to increase testing for CKD in this high-risk population,” said Kerry Willis, PhD, Chief Scientific Officer. “Our hope is that a home-based test makes it easier for patients at risk for CKD to comply with regular albuminuria screening, and that this will lead to earlier diagnosis and treatment of CKD, reducing cardiovascular risk and preserving kidney function.”

The trial will: Examine the effect of mailed, Healthy.io smartphone urinalysis kits to improve albuminuria screening compliance and detection of albuminuria.

Examine the feasibility of pharmacists

in improving management of detected albuminuria. Pharmacists will be instructed to confirm test with urine ACR and treat albuminuria.

Randomize 1,000 non-diabetic patients with hypertension who are receiving primary care at Geisinger.

A home test mailed to 500 Geisinger patients diagnosed with HBP but who do not have diabetes, along with instructions for downloading the smartphone app, to determine if the patient also has CKD.

Geisinger patients will receive a letter and phone call educating them on the importance of screening for proteinuria from a team of Care Gaps nurses. Follow-up will be managed by the patient’s primary care provider and care team.

“Healthy.io is proud to pioneer its ‘adherence as a service’ platform with such forward-looking institutions as Geisinger and the National Kidney Foundation,” said Yonatan Adiri, CEO of Healthy.io. “Our mission is to use advanced computer vision and patient centric design to let clinicians empower their patients at scale without additional cost or effort.” “Like a Netflix for adherence we lean on the spread of digital technology and efficient logistics to offer on demand testing delivered directly to the home. With a smartphone in your pocket, the point of care becomes wherever you are.” The clinical trial started April 16.

For the full article, visit <https://www.kidney.org/news/using-home-test-kit-and-smartphone-to-test-kidney-disease>