

How to Use *In Control*

Each issue of *In Control* offers background, tips, and patient education material on one topic that is important to living well with kidney disease. The 2-in-1 format of *In Control* is designed to make it easy to find the information and share it with your patients.

For you, there are 4 pages of professional content (pages S1, S2, S7, and S8), along with practical tips for putting key concepts into practice.

For your patients, there are 4 pages (S3–S6) of easy-to-read information.

We encourage you to make copies of *In Control*.

Use it to supplement your own education materials, and call us at (800) 468-7777 if you want to reprint an article. Help your patients get “in control” of their kidney disease!

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Sleep Problems and CKD

“...getting a good night’s sleep is as important for our patients as we think it is for our children.”

—Paul Kimmel, MD,
NIDDK and NIH¹

Good, restful sleep is so important to a healthy life that the Institutes of Medicine recently published a special report on the public health significance of sleep, sleep loss, and sleep disorders.² The report estimates that 50-70 million Americans suffer from chronic sleep disorders, with associated medical costs of “hundreds of billions of dollars a year.”

Among people with chronic kidney disease (CKD), the prevalence of sleep disturbances has been estimated to be as high as 80%.³ These sleep concerns take a variety of forms, are attributable to many causes, and can take a serious toll on patients’ health and quality of life.

Types of Sleep Problems

CKD sleep problems can take several forms. The most common are:

- **Insomnia**—trouble falling asleep, staying asleep, and/or early morning wakefulness. The diagnosis is primarily clinical and relies on a detailed history of sleep habits and, sometimes, data from a sleep diary.³ Insomnia affects an estimated 30-70% of people with CKD.³

- **Restless legs syndrome (RLS)**—an irresistible urge to move the legs, which is worse at night, and is temporarily relieved with movement.⁴ RLS is almost always associated with another movement disorder called Periodic Limb Movements in Sleep (PLMS);⁵ diagnosis is clinical and is based on four criteria (see *RLS* on page S2.) RLS affects from 60-80% of people with CKD.⁴
- **Sleep apnea syndrome (SAS)**—disordered breathing during sleep including periods of apnea, heavy snoring in most cases, restless sleep, fragmented sleep structure, frequent awakening, morning headache, personality or mood changes, and daytime sleepiness.⁵ Definitive diagnosis requires a formal sleep study, but clinical signs may be suggestive. SAS affects about 50% of people with stage 5 CKD.⁶

Serious Consequences

Although medical science cannot fully explain what happens when we sleep, research has shown that important metabolic functions occur, and that lack of sleep is associated with loss of immune functions.⁷ Further, sleep disorders cause excessive daytime sleepiness, impair daytime functioning, and reduce quality of life.

In people with CKD, sleep disorders have been associated with serious
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Restless Legs Syndrome (RLS)

As many as 8 in 10 people with stage 5 CKD have restless legs syndrome (RLS) or a related movement disorder called periodic limb movements in sleep (PLMS).¹ These conditions commonly disrupt sleep and can significantly impact employment, social activities, and quality of life.^{1,2} RLS and PLMS have also been associated with increased risk of death.²

Symptoms

RLS causes an irresistible urge to move the legs, and in most people causes sensations described as “tingling, aching, burning, pulling, itching, and/or cramping.” RLS is typically worst when patients are lying still, for example at dialysis. These symptoms can be so uncomfortable that patients may choose to end dialysis sessions early.

Research into the basis of RLS is ongoing; studies have linked it to a lack of proper response to dopamine in the brain and central nervous system. This dysfunction may be related to impaired iron metabolism, uremia, anemia, and/or neuropathy. Whatever the cause, RLS affects a disproportionate number of people with CKD. Symptoms may appear before patients reach stage 5, and often lessen after transplant.² Factors associated with RLS in the dialysis population include female gender, years on dialysis, body weight, underdialysis, vitamin deficiency, hyperphosphatemia, and iron deficiency.¹

Diagnosis

Specific diagnostic criteria established by the International Restless

Legs Syndrome Study Group (IRLSSG)³ include:

- An urge to move the legs, usually accompanied or caused by uncomfortable and unpleasant sensations in the legs
- The urge to move or unpleasant sensations that:
 - Begin or worsen during periods of rest or inactivity, such as lying or sitting
 - Are partially or totally relieved by movement
 - Are worse in the evening or at night than during the day or only occur in the evening or at night


Treatment

The treatment of RLS with prescription medication is common, but not all patients need medication. Several steps should be taken first:

- **Rule out RLS** that may be caused by medications, including certain antidepressants, over-the-counter cough and cold remedies, and some anti-seizure drugs. Alcohol, tobacco, and caffeine may aggravate RLS.
- **Manage anemia**, including adequate erythropoietin and iron supplements. Anemia treatment has been shown to reduce the prevalence and severity of RLS.²
- **Improve sleep habits** to help patients fall asleep and stay asleep. Good sleep habits include a regular bedtime routine that encourages relaxation and restfulness. Module 12 of Kidney School (www.kidneyschool.org)

has excellent tips about how to develop a soothing sleep routine.

- **Use comfort measures**, including warm baths, massage, or warm/cool compresses on the legs. Some patients find that relaxation techniques, like deep breathing or visualization, can also help reduce symptoms.

If these methods don't work, clinicians can turn to a variety of drugs that have proved useful. The choice and dosage will depend on the symptom severity and frequency (intermittent or daily). Current recommendations suggest dopaminergic therapy, including pramipexol (Mirapex[®]), ropinirole (Requip[®]), pergolide (Permax[®]), or cabergoline (Dostinex[®]) as first-line treatments for RLS.² Gabapentin (Neurontin[®]) might be useful for those with painful RLS.² Referral to a sleep specialist should be considered for patients with persistent, unresolved symptoms. 

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Q & A:

Ask the Expert

An interview with John J. Sim, MD

Staff Nephrologist, Kaiser Permanente Los Angeles Medical Center, Los Angeles, California

Dr. Sim and his colleagues at Kaiser's Los Angeles Medical Center have been studying sleep apnea in people with chronic kidney disease (CKD) for several years.

Q: Why is sleep apnea such an important issue for people with CKD?

Sleep apnea deserves attention because it is not an uncommon condition in the general population. It is estimated that 50-70 million people suffer from sleep disturbances including sleep apnea. Our research findings indicate that sleep apnea is even more common in people with CKD. Our studies demonstrated that CKD patients were more likely than people with working kidneys to have sleep apnea—even before they begin dialysis. The same is true after transplant. In dialysis patients, the high prevalence of sleep apnea is well described. Unfortunately, sleep apnea is associated with many serious health problems, including hypertension, stroke, heart disease, and even death. That combination puts many of our patients at risk.

Q: What can dialysis professionals do to alleviate those risks?

Early diagnosis and treatment offer hope of preventing the ill effects associated with sleep apnea. Because we know there is a higher than normal prevalence of sleep apnea in CKD, we should set a lower threshold for screening, diagnosis and treatment.

At Kaiser Los Angeles, we recommend a heightened vigilance for signs and symptoms of sleep apnea—especially in patients who are referred to nephrology for difficult to control hypertension and in patients who are obese. A good clinical evaluation involves observation, as well as asking patients about some common symptoms of sleep apnea, including:

- Morning headache
- Daytime sleepiness
- Fatigue
- Loud snoring (especially as reported by sleep partners)

In some cases, dialysis staff and/or sleep partners have actually observed patients stop breathing during sleep. They should be asked to report these observations to the nephrologist. Dialysis technicians should also be asked to report episodes of oxygen desaturation during dialysis (on machines with oxygen monitors, desaturation during dialysis will set off an alarm).

The presence of any of these symptoms suggests sleep apnea, and will prompt our team to consider a full sleep study in order to make a diagnosis.

Q: What should patients know about sleep apnea?

A: Patients should know that a

diagnosis of CKD means that they are more likely to have sleep apnea, and they should be asked to report persistent sleep problems to their dialysis team. Even if they cannot learn and remember the symptoms of sleep apnea, patients should talk to their nephrologist if they cannot function because they regularly do not get a good night's sleep.

Treatment, whether it comes in the form of behavior changes, a CPAP machine, or other interventions can help, and patients should be aware that help is available. We never want patients to suffer in silence, especially since there may be serious health consequences and we can do something to help.

Q: Why do you think it is so important to treat sleep apnea in people with CKD?

In the short term, treatment will improve patients' quality of life. They will be less tired, and just feel better if they are getting good quality sleep. In the long term, we hope to prevent or diminish damage to the body and internal organs caused by sleep apnea. In fact, the high prevalence of sleep apnea in people with CKD has led us to wonder whether sleep apnea itself may be a risk factor for CKD. If that is the case, treatment might actually stabilize the progression of kidney disease. 🌐

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health consequences, including increased morbidity and mortality.³ Sleep apnea increases the risk of hypertension, coronary artery disease, and stroke.⁶ At least one study has linked RLS/PLMS in stage 5 CKD patients with reduced quality of life and an increased risk of death.⁵ Insomnia, too, has been associated with significant psychological distress and reduced quality of life.³

Raising Awareness

Despite the high prevalence of sleep problems in the CKD patient population, these problems (and their impact on patients' lives) often go unrecognized and untreated. Why? In many cases, symptoms—daytime sleepiness and fatigue, for example—are mistakenly attributed to CKD itself or to comorbid conditions.⁶ Too, busy healthcare professionals often fail to ask about patients' sleep patterns and habits⁸—and patients themselves may not think to report sleep problems.


Greater awareness of the need for diagnosis, as well as the use of tools like the Berlin Questionnaire, can help practitioners better identify sleep disorders in their patients with CKD. When a diagnosis is made, patients are much more likely to receive effective treatment.

Providing Relief

Once a sleep problem is identified, professionals can prescribe appropriate interventions. In many cases, treatments will be directed at the underlying cause(s). For example, pain or itching can prevent restful sleep. For many patients, practicing good sleep habits—and resisting the tendency to nap—can greatly improve sleep quality.

A thorough description of treatments for sleep problems is beyond the scope of this brief article. It should be noted, however, that for sleep apnea, the use of CPAP (continuous positive airway pressure) therapy can provide dramatic benefits.⁶ And, for stage 5 CKD patients, more dialysis—especially nocturnal hemodialysis—has been shown to reduce breathing problems that occur during sleep.⁶

The knowledge that many people with CKD are suffering from sleep problems should put every caregiver on

the alert for signs and symptoms. Making a diagnosis starts with the most basic first step—asking about sleep. The answer could make a big difference in your patients' quality of life. 

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Additional Resources

For more sleep information, consult the following resources:

- Kidney School Module 12: *Staying Active with Kidney Disease* at www.kidneyschool.org
- The National Sleep Foundation at www.sleepfoundation.org
- *Nephrology Nursing Standards of Practice and Guidelines for Care* (ANNA, 2005)
- The RLS Foundation at www.rls.org

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In Patients **CONTROL**

A Medical Education Institute/Life Options Publication

VOL. 3 | NO. 4
DECEMBER 2006

Getting a Good Night's Sleep with Kidney Disease

Adults spend 33% of their lives asleep—but that's not the case for many people with kidney disease. Kidney disease and its treatment can cause sleep problems such as restless legs syndrome, sleep apnea, pain, and itching. The lack of sleep leads to low energy and strength, moodiness, and even depression.

Since sleep is vital to good health and living well, let's explore some sleep issues that people with kidney disease face, as well as tips for getting a good night's sleep.

Restless Legs Syndrome

Restless legs syndrome (RLS) is a “creepy-crawly” feeling in the legs. People with RLS have to get up and move around many times during the night to feel better. This means little or no sleep and feeling tired the next day. RLS can also occur with periodic limb movements in sleep (PLMS). PLMS causes legs to jerk as often as every 20 seconds.

If you think you have RLS, talk to your doctor. There are medications that can help some

people who have RLS. You can also rub or massage your legs, take a hot bath before bed to relax your muscles, and/or ask your doctor to refer you to a neurologist (a doctor who specializes in nerve problems). One of the best ways to fight RLS and PLMS is by getting regular exercise! Exercise increases blood flow to your legs, which helps reduce symptoms in most people.

Sleep Apnea

Sleep apnea causes breathing to stop during sleep—from several times an hour to 200 or more times a night. When breathing stops, the brain sends a message to “jump-start” breathing by waking the sleeper with a “snort.” Sleep apnea is harmful because research has shown that sleep apnea is a risk factor for health problems, like high blood pressure, stroke, heart disease, and diabetes.

If you think you have sleep apnea, ask your doctor to suggest a sleep clinic. A sleep clinic will test you. If you have sleep apnea, you will likely be treated with a continuous positive airway pressure device (CPAP). A CPAP is a mask that fits over the nose and/or mouth, and gently blows air into your airway to help keep it open during sleep. Other things

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Struggling to Sleep

Sleep problems affect many people on dialysis. Read what three of them have to say:

Ralph, 71, Nocturnal Home Hemodialysis (NHHD)

A trip to the hospital for congestive heart failure in 2001 led to a diagnosis of kidney disease and sleep apnea for Ralph. “For years, Ralph had a hard time sleeping,” reports Pat, Ralph’s wife of 42 years, “but after testing, he got a BiPAP machine and sleeps like a baby.”

In June 2003, Ralph’s kidneys failed. “Ralph did his first treatment in the hospital,” says Pat. “After that, he drove himself to in-center dialysis for a year.” Ralph often had symptoms of restless legs syndrome (RLS) as well as cramping. “We mentioned the RLS to the doctor, who suggested medication,” says Pat. “Ralph tried it, but it didn’t work, so he lived with the symptoms.” Pat says in some ways *she* was bothered more by the RLS than Ralph was, “because his legs were constantly moving during the night!”

Because Ralph was tired after dialysis, it was hard for him to drive to and from treatments. That’s when Pat began to question Ralph’s treatment choice. “The staff at the center had talked about NHHD, so I began to learn all I could about it,

even going to on-line message boards.”

In June 2004, Ralph switched



to NHHD. “Since I started NHHD, my lab results are better, I feel better, and my sleep problems have subsided,” states Ralph. Pat adds that Ralph was itchy all the time on in-center hemodialysis, but now needs to *add* phosphorus during his treatment because he gets so much dialysis. “Home dialysis is a lot of work, but well worth it,” they report.

Ralph and Pat suggest that anyone with sleep apnea symptoms get tested at a sleep lab. They also suggest education. “When you learn you have kidney failure, you have to keep upbeat and learn all you can,” advises Pat. “Dialysis is not the end of the road—there is an amazing and wonderful life on dialysis!”

Lori, 41, Continuous Cycling Peritoneal Dialysis (CCPD)

Lori was diagnosed with kidney disease in 1988. Since that time, she has done in-center hemodialysis, had two transplants (one for 15 years), and now does continuous cycling peritoneal dialysis (CCPD). “I do PD from midnight to 7 a.m., with a 20-minute exchange at 7:30 p.m.,” says Lori. “I also do 2-3 manual exchanges during the day to get better dialysis.”

When she first started CCPD, Lori wasn’t comfortable with the fluid in her abdomen. “Sometimes, I’d end up laying on the tubes and the alarm would go off,” she remembers. “Otherwise, the noise from the machine doesn’t really bother me—but my husband has to sleep in the guest room some nights!”

RLS has been a struggle for Lori, in fact, she quit her full-time job as an interior designer because of it. “I’m very tired because I can’t sleep at night,” reports

Lori. “Also, I have to be home by 7:30 p.m. which makes it hard to work retail.”

Lori watches TV standing up when she is having symptoms of RLS. “It messes up my whole schedule,” says Lori. At first, Lori tried taking medication for the RLS, but felt nauseous and stopped. She later found the true reason for her nausea: a problem with one of her kidneys. “I had surgery to remove my bad kidney, and the pain medicine really helped me sleep!” Since then, Lori has tried the RLS drug again, and her RLS symptoms have improved.

Lori decided to learn more about RLS and went to the Internet for information. “I found an article linking salt intake to RLS, so I try to limit salt. I’ve tried relaxation tapes, too, which worked sometimes.”

Since reducing her salt intake and adding manual exchanges, Lori’s lab values have improved and her RLS symptoms have gotten better. “You have to get information to ask your doctor questions and make changes that will help you feel better,” Lori explains. “Most important, know that you are not alone.”

Glen, 75, In-center Hemodialysis

“Kidney failure has affected our lives completely,” says Caroline, Glen’s wife of 55 years. Glen, who has a hearing problem, was diagnosed with kidney failure in March 1999, and has been on in-center hemodialysis since then. Glen has also been affected by a lack of sleep.

While Glen has never had RLS, he tosses, turns, and snores all night. “About 5 years ago, the center staff noticed that Glen wanted to sleep during his treatment and do nothing

else,” recalls Caroline. “He was also snoring, so the staff suggested he get tested for sleep apnea.” Glen did get tested and was put on a CPAP device. Caroline reports that, “Glen doesn’t want to use it because he tosses and turns all night and the cord winds around him.” Glen also says the nose prongs come out during the night and end up poking him in the eye.



Since Glen sleeps poorly at night, he takes 1-2 hour naps throughout the day. “He carries on, but I think he gets depressed with the sleep and hearing problems,” says Caroline. Glen’s sleep problems have taken a toll on Caroline, too. In addition to the tossing, turning, and sleep apnea, Glen now talks in his sleep all night long. “I hear him snoring and talking and it gives me broken sleep, too,” says Caroline, adding, “Luckily I am the kind who doesn’t need a lot of sleep, but I sure am dragging by 8:30 p.m. or so!”

A solution to Glen’s sleep problems may be on the horizon: Glen recently started physical therapy to help him walk and strengthen his leg and arm muscles. “He still snores, but I’ve already noticed that he doesn’t sleep as much during the day and sleeps better at night,” reports Caroline. “I think the exercise has given him more energy. A few days ago he stayed up all day without a nap for the first time in over a year!”

To read more about Ralph and Lori, visit the Patient Stories section of the Home Dialysis Central website at www.homedialysis.org.

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Getting a Good Night's Sleep with Kidney Disease

you can do to help reduce apnea severity are:

- Lose weight
- Avoid alcohol
- Quit smoking
- Sleep on your side, not your back

Other Sleep Problems

Pain due to arthritis, nerve pain, etc. is another common reason for a poor night's sleep. If pain disrupts your sleep, talk with your doctor about over-the-counter or prescription medicine that can help. Also, moderate exercise and stretching can help some types of pain.

For people with kidney problems, itching can keep you from sleeping or wake you up. Dry skin, high levels of phosphorus in the blood, or a buildup of other toxins can make skin itchy.

Getting a Good Night's Sleep

Sleep problems are common for people

with kidney disease. Sometimes, all it takes to fix them are simple changes.

Try to:

- Keep a regular sleep-wake schedule
- Exercise at least a few times a week (but at least 4 hours before bed)
- Avoid caffeine
- Take a hot bath 90 minutes before bed
- Keep your bedroom quiet and comfortable

If nothing seems to help, a number of sleep medicines can be used by people with kidney disease. Talk to your doctor to see if one is right for you.

Where Can I Learn More About Solving Sleep Problems?

You can learn more about sleep problems on the Internet. Visit:

- The RLS Foundation at www.rls.org
- The National Sleep Foundation at www.sleepfoundation.org

For More Information...

To learn more about sleep problems and kidney disease, visit Kidney School Module 12: *Staying Active with Kidney Disease* at www.kidneyschool.org. Topics discussed include RLS, sleep apnea, itching, and cramping, as well as tips to help with symptoms and the benefits of exercise.

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