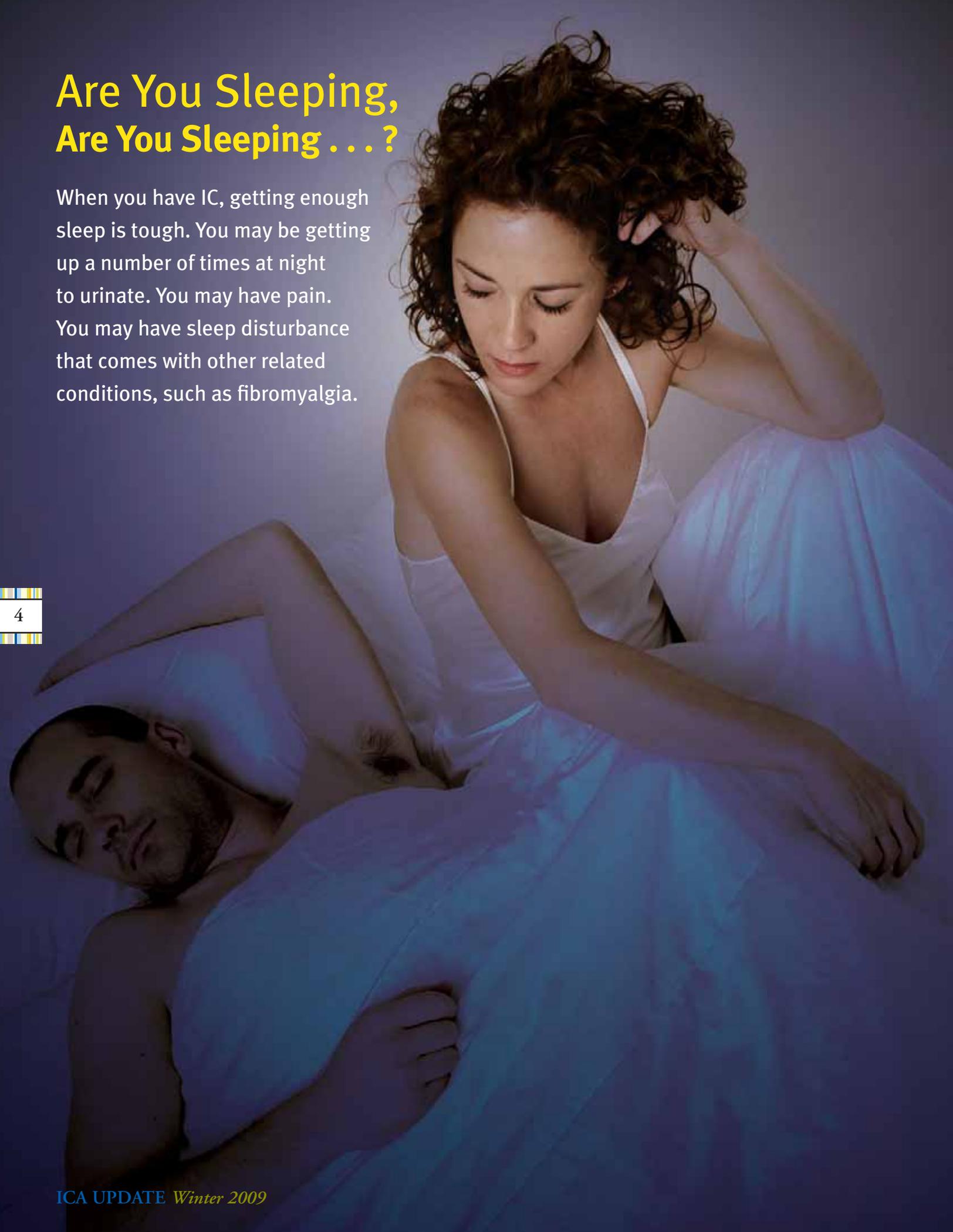


Are You Sleeping, Are You Sleeping . . . ?

When you have IC, getting enough sleep is tough. You may be getting up a number of times at night to urinate. You may have pain. You may have sleep disturbance that comes with other related conditions, such as fibromyalgia.



What can you do about it? The IC experts, sleep experts, pain experts, and researchers that the *ICA Update* looked to for advice all said there's no sure-fire solution. To find better ones, we need to know much more about IC patients' sleep problems. Nevertheless, there are numerous medical therapies and self-help techniques that may help you get more of the sleep you need. You need to be your own detective to find what combination works for you.

A recent sleep survey brought home how hot the sleep issue is for IC patients and how little we know about it. In less than two weeks after notice went out in the ICA's electronic news digest, *Café ICA*, more than 700 of you responded. Aimed to answer questions about exactly what robs IC patients' sleep, the survey is part of Alis Panzera, CRNP's research for her nursing doctorate. Panzera, who cared for IC patients in Kristene Whitmore, MD's practice in Philadelphia before she went back to school, knew this was a big problem for her patients, but she didn't have much to offer them because there was no research. Hers will likely be the first study specifically on IC and sleep.

Although her survey will tell us about IC patients overall, you probably have a good idea what wakes *you* up and keeps *you* awake. That's where to start your own problem solving.

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Calm Your Bladder

“In most instances, IC patients' sleep is simply disturbed by the need to urinate,” said Robert Moldwin, MD, Director of the Pelvic Pain Center at Long Island Jewish Medical Center in New Hyde Park, New York. “This may be related to pelvic pain or discomfort, but in some instances, to a low bladder capacity.” So, the best therapy for IC patients' sleep, he said, is adequate IC treatment.

Take a look at whether you're getting the most effective treatment you can for your bladder symptoms. Sometimes, doctors prescribe only one medication or therapy, but there are many treatments that can help reduce frequency and pain. The tricyclic antidepressant amitriptyline (Elavil) and the antihistamine hydroxyzine (Atarax, Vistaril) have become IC standards, and they also make you sleepy, so taking them in the evening can help. Bladder instillations, especially those with anesthetics, can calm your bladder quickly, so if you do them yourself, doing them before bed could keep your

bladder from waking you up. If you use muscle relaxants, such as diazepam (Valium) orally or intravaginally, try using them before bed as well. Oral diazepam also has the advantage of making you sleepy. If you use any home physical therapy techniques or exercises aimed at relaxation, do those in the evening.

Stages of Sleep

Sleep occurs in a succession of stages that takes about 90 minutes and recurs through the night.

Stage 1: Drowsiness

Stage 2: Light sleep

You lose awareness of your surroundings.

Stage 3 (and 4): Deep sleep

(Recently, the American Academy of Sleep Medicine combined these as stage 3, but you may still hear about stages 3 and 4.) This stage is sometimes called “delta sleep” because this is when the slower delta brainwaves occur. This is a period of body repair and restoration when blood flow decreases to the brain and increases to the muscles, and immune function increases.

Rapid Eye Movement (REM) sleep

This is the dreaming stage. Dreaming, while a very active form of sleep not considered deep sleep, may help you process emotions, retain memories, and relieve stress.

To feel rested, you need enough stage 3 and REM sleep. But if your symptoms wake you, you have to go through stages 1 and 2 again to get to those restorative stages, so you end up having less sleep time in those stages. That may exacerbate pain and contribute to feeling out of sorts, anxious, or even depressed.

Treat Your Pain

Getting your pain under control is crucial for your sleep, and sleep is crucial for your pain control. Pain and sleeplessness can be a vicious cycle. Although there's no solid proof yet that chronic sleep deprivation causes pain, “there is evidence that if you have pain and you don't have quality sleep, your pain is worse,” Lynn Webster, MD, told the *ICA Update*. Dr. Webster is Medical Director of the Lifetree Clinical Research and Pain Clinic in Salt Lake City, Utah.

If you know that it's pain that wakes you and pain that keeps you from getting back to sleep, then you need to work on

getting your pain treated adequately. Too often, that's a hurdle for IC patients, especially when their pain is bad enough to require opioid medications. If you need more pain control, get a referral to a pain center if you can, or ask your doctor to get advice on your case from a pain specialist.

Take Sleeping Pills?

When treatments for frequency, urgency, and pain don't help sleep enough, physicians may turn to some of the newer sleep medications, the nonbenzodiazepine hypnotics, such as zolpidem (Ambien), zaleplon (Sonata), and eszopiclone (Lunesta). These are best at getting you off to sleep, although eszopiclone is thought to maintain sleep better than the others.

Sometimes, they can be the charm. Teresa McCoy from Albuquerque, New Mexico who takes eszopiclone, said, "I probably would not be able to sleep without it." But that isn't true for many other patients. "I rarely saw success with some of the highest doses of Ambien and Lunesta," Panzera said.

The Trouble with Treatment

The trouble is that many of the medications that are useful in IC may help you get some sleep, but not enough restorative, quality sleep (see "Sleep Stages"). And some medications, especially when taken together, pose health risks.

Benzodiazepines, such as diazepam, act as muscle relaxers and can be very useful in IC because spasms of the bladder's own detrusor muscle as well as tight muscles, such as the pelvic floor, contribute to your symptoms. Daniel Brookoff, MD, PhD, at Presbyterian-St. Luke's Hospital in Denver, Colorado, prescribes fairly high

doses of oral diazepam to be taken at night. "It appears to have a specific effect on the detrusor muscle," he said, which is why he prefers it to other benzodiazepines.

Benzodiazepines make you sleepy as well and were commonly prescribed for sleep before newer sleep aids came along. But one drawback for people who take them is that they tend to spend more time in light sleep (stage 2) and less time in restorative deep sleep (stages 3 and 4).

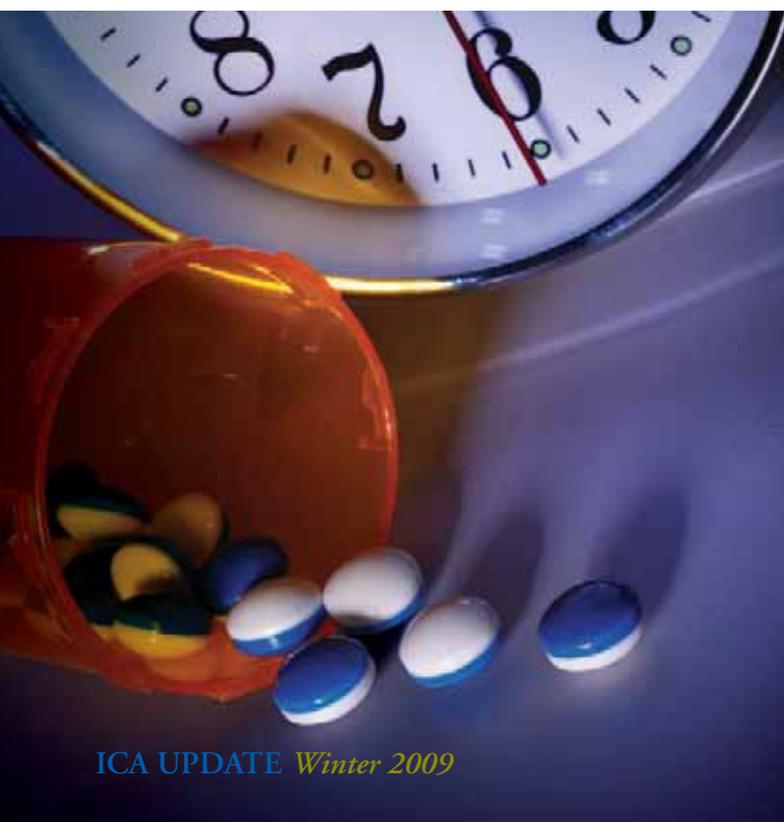
IC patients sometimes have prescriptions for more than one benzodiazepine, since these drugs have other uses, such as for anxiety. Because they act so much alike, "they become very interactive" and may also be less effective, cautioned sleep specialist Robert Ballard, MD, Medical Director of the Advanced Center for Sleep Medicine at Presbyterian-St. Luke's Medical Center in Denver, Colorado.

"I try to get people on as simple a medical regimen as possible," he said. That's why he has some of his IC patients take just one longer-acting benzodiazepine, clonazepam (Klonopin) at night.

Short- and long-acting opioids can be very effective at reducing pain and promoting sleep (although some can act as stimulants). But opioids also carry sleep hazards that have only recently come to light. Dr. Webster and other sleep specialists in Salt Lake City and Australia found that moderate to high doses of opioids carry a risk of a dangerous "central" sleep apnea. That's the kind where the brain stops sending the signal to breathe, not the kind that comes with snoring. In his experience, said Dr. Ballard, that effect isn't tied to the degree of pain control or the effect on consciousness, so you and your doctor need to be cautious, even when you don't feel "zonked."

Although methadone, said Dr. Webster, has been associated with a greater risk of sleep apnea than some other opioids, they all carry this risk. He doesn't say don't use them at all. "It's not bad by itself that the opioids induce a sleep apnea. It's bad if we don't know about it and don't treat it." Rather, he recommends sleep studies for anyone on moderate to high doses. A sleep study, usually done at a sleep lab, monitors your breathing and other body functions while you sleep—or try to—and lets your doctor know whether you might need help breathing at night, such as with a continuous positive airway pressure (CPAP) machine.

Dr. Webster is also concerned about combining opioids with sleep aids, even the nonbenzodiazepines. "You have to minimize, if not avoid, any of the benzos or benzo-like products or you increase your risk of sleep apnea, hypoxia [oxygen deficiency], and death," he said. Again, he urged sleep studies.



Dr. Webster tries to avoid problems with these drugs by prescribing anticonvulsants instead for his IC and other pain patients. Most often, he uses a high single dose of gabapentin (Neurontin) or pregabalin (Lyrica) at night. He also finds amitriptyline as well as trazodone (Desyrel) helpful for sleep.

You may have heard about other side effects with the nonbenzodiazepine sleep drugs, such as sleep walking, sleep eating, or even sleep driving. Dr. Ballard noted that more of those reports concerned zolpidem, and the effects seemed to occur less often with eszopiclone. Plus, he said, eszopiclone has been fairly well studied in chronic pain, such as rheumatoid arthritis or cancer pain. And it may prove helpful in fibromyalgia. In fact, some trials are ongoing. But Dr. Ballard, too, will often prescribe amitriptyline or trazodone.

Wave of the Future?

Most medications that aid sleep do a pretty good job of helping you get there but not a great job in increasing restorative sleep. For people who have pain, especially fibromyalgia and chronic fatigue syndrome, which are intimately linked with sleep disturbance, a better sleep drug would promote more delta wave (stage 3 and 4) and REM sleep.

One drug on the market already does increase deep sleep—sodium oxybate (Xyrem), also known as gamma hydroxybutyrate or GHB. But the drug is approved only for certain symptoms in people with narcolepsy, a disorder that causes people to fall asleep suddenly. Although doctors can prescribe drugs “off label,” it’s not easy for doctors to prescribe it for other sleep problems because it is tightly controlled, since it can be a street drug. Not many insurers cover it, and it is very expensive.

GHB “may be the best sleep drug we have. But it has to be carefully managed. We need more studies and a broader indication so that we can use it in more patients.”

Lynn Webster, MD, Lifetree Clinical Research and Pain Clinic

“It may be the best sleep drug we have,” said Dr. Webster, who thinks it could benefit some IC patients, especially those with fibromyalgia. “But it has to be carefully managed. We need more studies and a broader indication so that we can use it in more patients.”

As a pain specialist certified in addiction medicine, Dr. Webster does know how to manage the therapy and looks forward to results of trials going on now. Placebo-controlled clinical trials

have already shown reduced pain and fatigue and better sleep for fibromyalgia patients, and stage 3 clinical trials aimed at FDA approval for fibromyalgia are ongoing.

Newer drugs are on the way that act similarly to the nonbenzodiazepine sleep medications but may be do a better job of improving sleep quality. Also, sleep drugs that are relatives of gabapentin and pregabalin are in the pipeline. Drugs that block a certain serotonin receptor also look promising because they seem to increase both deep and REM sleep. It’s not clear what effect these drugs may have on pain, but other drugs that act similarly are in the pipeline for pain. Also looking promising is a drug that blocks the receptor for the nervous system hormone orexin and increases sleep time and the percentage of REM sleep.

Restoring wakefulness, in addition to good quality sleep, should also be a concern in treating IC patients with sleep problems, said Dr. Brookoff. One drug already on the market, modafinil (Provigil), has shown benefits in fibromyalgia. Today, it is used to promote wakefulness in people with narcolepsy, obstructive sleep apnea, or who do shift work. Provigil’s longer-acting relative armodafinil (Nuvigil) was approved in 2007 and is being studied in fibromyalgia.

What about Supplements?

All the experts the *ICA Update* spoke to demurred about herbals and supplements. The American Academy of Sleep Medicine said herbal supplements shouldn’t be used unless you consult with your doctor and warned of the risks of side effects and interactions with other drugs you might be taking. That’s good advice for IC patients, since they often take a number of medications, can be very sensitive to medications and supplements, and tend to have allergies. Check out anything you are interested in using with your doctor and your pharmacist.

Supplements just haven’t been well studied for effectiveness, Dr. Ballard pointed out. “I’m always reluctant to encourage people to use medicines that they have to pay real money for that haven’t been studied adequately.” He noted that melatonin has been the best studied. It has been helpful for people with clock problems and seems to be able, at high doses, to make people sleepy during the day. At night, however, it doesn’t seem to induce sleep.

L-tryptophan was a popular sleep supplement but was taken off the market because of severe side effects that may have been caused by contamination. The supplement is available again, but concerns remain, so Jill Mushkat, PhD, a consultant psychologist in pain management at the Cleveland Clinic in Cleveland, Ohio, steers her patients toward natural sources, such as milk or other protein foods along with some carbohydrate, such as a cookie, which helps release tryptophan.

Do-It-Yourself Sleep Tricks

Advice on how to improve your sleep without medication is so common, “You’d have to live in a cave not to hear it,” wrote Gayle Greene, author of the acclaimed book *Insomniac*, an insightful look at the world of sleep research and treatment from a patient’s perspective. She points out that the focus on the behavioral approach has a lot to do with the combination of a mysterious and invisible medical problem, a predominance of women patients, and dismissive physicians and researchers, a scenario familiar to IC patients. Although behavioral therapies and “sleep hygiene” are touted as successful, the American Academy of Sleep Medicine didn’t rate them as highly effective, noting that few studies have shown them to be better than placebo, Greene pointed out.

But for patients with severe symptoms and chronic pain who may be taking painkillers, benzodiazepines, and other medications already, “it’s not really easy to add much to the armamentarium,” said Dr. Ballard, which is one reason he helps patients take advantage of behavioral therapies. And, as one psychiatrist told author Greene, “It’s the part we *can* change.”

Similarly, Panzera said that, because there she didn’t have effective, targeted strategies to help IC patients sleep and because IC patients tend to be so sensitive to medications, these techniques were often the best help she could offer.

They may go farther than you might think. After all, Dr. Mushkat pointed out, you may not realize how much the change IC has made in your lifestyle has affected your sleep. For example, if you’re no longer working, you’re probably not as physically active as you once were, and you need a certain amount of physical activity to get tired enough to sleep.

The idea behind most of the recommendations, Dr. Ballard explained, is not to straightjacket you into particular habits but to avoid stimulation that keeps you awake.

Find What Works

What’s important for getting more of the sleep you need, said Panzera, is to do whatever works for *you*. “That can be so variable from person to person. I really think that most IC patients have developed some good coping strategies. They know that if they do this, it bothers their bladder, but if they do the other, it really helps. So, do the other, especially before you go to sleep.”

That may mean doing your instillation in the evening, taking your medication at night, using some of these sleep tricks, or all of those. The key is to try and see what works for you. And in the future, you can look forward to better ways to get you to the land of Nod for as long as you need to be there. 

Try some of these sleep tricks that were at the top of these clinicians’ and researchers’ lists.

- Go to bed and get up at the same time every day, even weekends, and eliminate daytime naps.
- Exercise in the morning. Dr. Ballard said he finds morning exercise to be very helpful for promoting daytime alertness and improving nighttime sleep, so be sure to set your wake time early enough to work in your exercise.
- Take the stimulating gizmos out of your bedroom—the television, the computer, and even the alarm clock if you clock watch. That helps you reserve the bedroom for just sleep and sex.
- Cut caffeine, alcohol, and smoking. Because caffeine and alcohol bother so many IC patients, you may have eliminated them from your diet already, but if not, don’t drink caffeinated beverages in the afternoon or later and drink only one alcoholic drink in the evening with dinner. Smoking is not just bad for your health, it can also disrupt sleep because nicotine is a stimulant. Plus, there is evidence that smoking is a risk factor for IC.
- Start winding down an hour before bedtime. Turn off the news and the computer. Dim the lights. Put on soft background music. Read something that’s not gripping or do some activity that’s not stimulating, such as knitting or crocheting. Relax your muscles with your stretches or a warm bath.
- Don’t go to bed hungry. If you are hungry when you start your wind-down time, have a light snack, especially one that combines a high-tryptophan item, such as milk or a protein food, with a little carbohydrate.
- Then, relax. Right before bed is a good time to meditate, listen to your relaxation recording, or practice your relaxation technique.
- Keep your bedroom comfortably cool. When it’s too hot, people have more nighttime awakenings, less REM sleep, and less delta sleep.
- Try a 20-minute rule. Lying in bed awake is OK if you feel restful and feel like your body’s ramping down. But if you’re getting more and more alert as time goes on, leave the bedroom after about 20 minutes to do something nonstimulating. When you feel yourself winding down, go back to bed.