By Page Leggett
Contributing Expert:
Andrew Cook, MD

Chronic pelvic pain (CPP) affects more than 15 million women, yet its cause is often difficult to identify. In fact, the most common cause of chronic pelvic pain, endometriosis, requires surgery to diagnose.

Dr. Andrew Cook, a reproductive endocrinologist and surgeon in Los Gatos, California, is one of the country’s leading experts in CPP. Even Dr. Cook says diagnosing and treating CPP isn’t easy. “It’s like solving a puzzle with only half the pieces,” he said. “Each patient is different, and the causes are highly variable.”

Up to 15 percent of 18- to 50-year-old Americans endure chronic pelvic pain. Although the majority of suffers are women, CPP also affects men, particularly cyclists.

Patients with chronic pelvic pain are often misdiagnosed, under-treated or treated dismissively by health care professionals. “If you’re being written off and not getting answers, seek additional opinions. There is hope,” advises Dr. Cook. He regrets that many of his patients have already spent years looking for answers before coming to him.

A nurse’s wake-up call
Mary French, a registered nurse in Howard County, Maryland, is one of those people. French had a history of urinary tract infections when she became pregnant with her first child in 1987. During that pregnancy, the infections grew worse. French says, “My symptoms began with extremely intense burning, urgency and frequent urination.” As is common with CPP, her doctors didn’t initially diagnose her condition correctly. “My physicians chalked it up to ‘nerves’ and anxiety related to the pregnancy,” she recalls.
The same painful condition returned during French’s second and third pregnancy, and again when her youngest child turned one. Because bacteria was not present in her urine, doctors continued to tell French that nothing was wrong. They even implied that the problem was in her head. “I began a very frightening period of intense pain, multiple doctor visits and failed treatments,” she says.

It was years before her painful condition would be correctly diagnosed as interstitial cystitis (IC). “As a nurse, I had heard of interstitial cystitis,” she says. “But at that time it was still considered by many to be a psychosomatic, hysterical ‘female problem’ and not a ‘real’ medical issue.”

Playing detective

Even today, many physicians are stymied by chronic pelvic pain. The symptoms vary widely; so do the causes. Dr. Cook offers five likely contributors: endometriosis, interstitial cystitis (also described as “painful bladder” syndrome), internal scar tissue (adhesions), vulvar pain and pelvic floor muscle spasms.

Pelvic floor muscle spasms are probably the least recognized cause of chronic pelvic pain, but the easiest to treat. According to Dr. Cook, too few physicians are familiar with the connection between pelvic floor spasms and CPP. He recommends seeking relief through physical therapy. “A certified therapist can manually manipulate the pelvic floor muscles through the vagina,” says Dr. Cook. “Other methods include having patients do strengthening exercises of the muscles between the pubic bone and tailbone.” However, fewer than five percent of physical therapists in the U.S. have subspecialty training and are qualified to perform pelvic floor physical therapy. Dr. Cook also suggests using biofeedback to relieve pain.

According to Dr. Cook, effective diag-
nostic tests don’t exist if adhesions are suspected. But if CPP stems from endometriosis, a physician might prescribe birth control pills or put the patient into temporary menopause with a drug called Lupron. (This drug does not impact a patient’s ability to conceive.)

“Up to 40 percent of CPP sufferers undergo surgery to determine the cause of their pain,” Dr. Cook explains. In his practice, however, that figure is less than one percent. Many of his patients, some of whom have come from across the county, have been through an average of four surgeries and still haven’t found answers—or relief. Dr. Cook suggests there is an emerging theory that one of the ways to treat endometriosis surgically—coagulation, or burning the tissue—actually undertreats CPP. Excising the tissue, he says, may be a more effective surgical method. Unfortunately for the patient, the pain continues—sometimes even after multiple surgeries.

Chronic Pelvic Pain and Sex
It’s not surprising that along with physical and emotional issues, sexual intimacy is nearly impossible for women with CPP. Dr. Cook acknowledges, “CPP impacts every aspect of a person’s life—professional to intimate. Its effects are wide-reaching and can be devastating.” Sally, a 29-year-old newlywed, first experienced pelvic pain during sexual intercourse. She didn’t disclose the problem to her doctor right away, but after an extended menstrual cycle, she sought medical attention. Her diagnosis was chronic pelvic pain, with vulvodynia.

Sally’s treatment began with physical therapy to strengthen her pelvic floor. “The therapist attached electrodes to my pelvic muscles and asked me to contract and relax while visualizing the muscles on a computer screen. She also used her hands to manually manipulate the muscles,” Sally recalls. However, the physical therapy proved unsuccessful. Sally now uses Neurontin, in the form of a compound gel, which she applies three times daily inside her labia, but external to the vagina. Sally’s pain isn’t constant but occurs when the area is touched, especially during intercourse.

Sally reveals a common challenge for women who live with chronic pelvic pain: “My pain has made a healthy sexual relationship with my husband difficult.” Although her treatment has just begun, she remains hopeful. “I would advise others to hang in there. There are several different medication combinations out there, as well as physical and emotional therapies for individuals and couples,” she says.

Beyond the physical pain
Mary French reports that her pain felt as if someone was inserting a hot poker into her bladder. “I was afraid to urinate because it was like pouring alcohol on an area cut by razor blades, yet I constantly had that sense of urgency,” she says.

But chronic pelvic pain extends beyond the physical pain. French says she became depressed during her odyssey for a diagnosis and treatment. “There was shame and stigma related to this, which can be so damaging to those trying to heal.” One of the urologists she consulted prescribed Valium, which only added to her depression.

When pelvic pain leads to emotional and behavioral changes, the International Pelvic Pain Society (IPPS) identifies chronic pelvic pain as chronic pelvic pain syndrome because the pain itself has become the disease. At this point, the pain is a bigger problem than the original cause.

As both a CPP patient and a health care provider, French reflects, “We are beginning to learn much more about how common depression is with chronic pain. As health care providers, the most
damaging thing we can do is to remove hope. Traditional Western medicine focuses on ‘curing’ illness, and when we are unable to cure we have a tendency to abandon clients. We have many effective technicians, and not so many healers."

**When doctors don’t have answers**

When CPP patients get little relief or understanding from their doctors, many search for their own alternatives.

“I have tried many alternatives,” French says. “I believe that acupuncture and mindfulness-based stress reduction have helped me cope with pain.”

Dr. Cook says a low-tech approach may be just what the doctor ordered. “Seeing a nutritionist and altering your diet can make a big difference,” he says. He has also seen some success with vitamin D supplements.

In French’s case, she ultimately found a sympathetic doctor—and one who was well informed about CPP. Through hydrodistention of her bladder (a procedure done under regional anesthetic that distends the bladder with fluid to locate small hemorrhages in the bladder’s lining), the doctor confirmed what French had long suspected. She did have interstitial cystitis (IC).

“In a small percentage of patients, this procedure helps to reduce pain. I was one of the lucky ones who had a partial remission following this procedure,” French recounts. That “partial remission” has now lasted 14 years. She attributes her lengthy remission to the alternative treatments she sought.

Now a psychotherapist, Mary French leads a support group for people with chronic pain. After a physically and emotionally painful journey, she can be philosophical about her experience. She says, “I now view pain as a great teacher. It has helped me increase my compassion for others and strengthened my spiritual beliefs. I have learned to seek out the many resources available to improve my quality of life and health.”

1Endometriosis is an implantation and growth of endometrial (uterine lining) tissue outside of the uterus, which can result in a variety of problems, including pelvic pain or subfertility, depending on its location and extent.

2Name changed to protect privacy

3Vulvodynia is chronic discomfort or pain of the vulva, which is the area around the outside of the vagina. Researchers estimate that as many as 18 percent of women will experience symptoms consistent with vulvodynia.