The Sex Destroyer

Half of all men will suffer from prostatitis. Many will experience a pelvic pain so excruciating that sitting, sleeping, and even having sex will become impossible. Most doctors are helpless to stop it. Meet the few who know how. BY STEPHEN RAE

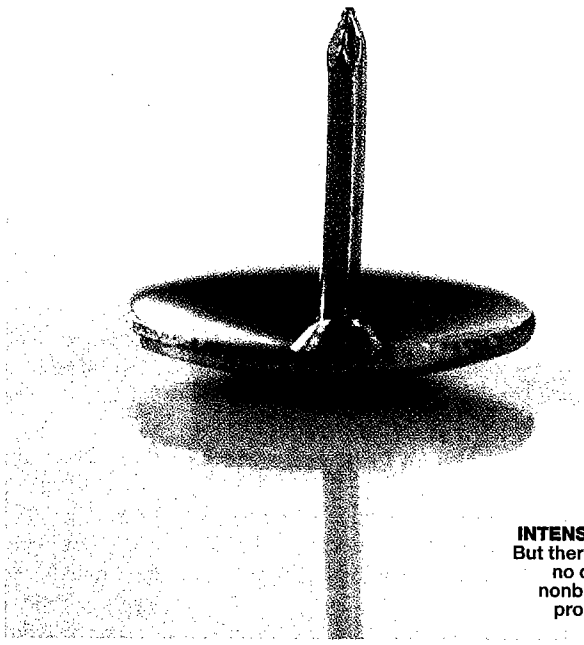
Deep in a redwood forest, at the end of a quiet country lane in California's Sonoma County, 12 men in their thirties and forties lie on mats in a carpeted room on the second floor of a seven-gabled, cedar-shingled lodge. Each is wearing headphones and eye pillows.

"Your pain is not your enemy. If you know how to listen to it, it will help you," David Wise, a 60-year-old clinical psychologist, intones into a microphone. Wise is leading a workshop, training participants in what is called paradoxical relaxation. "The more you are afraid of your pain, the more it will hurt," he says. "Fearing pain makes you more anxious and causes you to tighten up, which raises the level of electrical activity in your muscles and makes the pain worse, which causes more tightening, more anxiety, and more pain."

But the pain he describes is one from which any man would cower. This isn't a gathering of weekend athletes with strained hamstrings or high-powered execs with cluster headaches. These men suffer from prostatitis, a motley array of sexual, urinary, and pelvic-floor pains and dysfunctions that make daily life agony and orgasms feel like electric shock. Each has paid $3,800 for this six-day treatment, called the Stanford Protocol. Most would have paid twice that. "I was walking down the street one day when suddenly, out of nowhere, I got this ferocious pain in the tip of my penis, as if a ferret had clamped down and wouldn't let go," says a 47-year-old lawyer from Portland, Oregon. A 35-year-old actuary from Sacramento, California, wound up in the fetal position in the emergency room with testicular pain that felt "like I'd been kicked in the nuts."

Little known and poorly understood, prostatitis is men's big secret, the third most common reason we go to urologists, number one for men under 50. Because the disease is only now being seriously studied, there are no solid numbers on how many men suffer nationwide. One recent study showed that 11 percent of the men in one county in Minnesota had been diagnosed with prostatitis in recent years. A Canadian study found that 6 percent of men in two Canadian provinces had reported moderate to severe pain from prostatitis in the prior week. Four percent of Finns have it. "Half of all men will have a prostatitis experience sometime in their lives," says Rodney Anderson, M.D., codeveloper, with Wise, of the Stanford Protocol. Not all will become as sick as the men in the lodge, whose bizarre pains take severe tolls on relationships, careers, and lives.

It is a phenomenon I've come to know all too well.



INTENSE PAIN But there is still no drug for nonbacterial prostatitis.

When prostatitis hits, it instantly becomes the most important thing in your life. On Tuesday, I ran five miles. On Wednesday, a stabbing pain in my butt kept me from sitting down. And no one seemed to know how to help me.

As I would come to learn, my nightmare was all too typical. I was told an inadequately treated urinary tract infection had spread to my prostate. The stabbing pain was mercifully intermittent, but the intense bladder pressure was constant. Think of a time when you really, really had to go, maybe after six beers. Imagine feeling that way all the time. Imagine trying to fall asleep. The boor who was my first urologist said, "Look at you! You need a psychiatrist!" as I sat in his office distraught after three sleepless nights. He insisted on strict celibacy during weeks-long courses of antibiotics, but his office dispensed a flyer on the illness recommending frequent sex. Rightly perceiving me on the verge of collapse, my G.P. slapped me on Xanax, a cousin of Valium in the benzodiazepine family, which seemed to quiet the nerves that were firing abnormally in a way painkillers couldn't touch. It allowed me a few hours of sleep.

I saw another urologist, the head of the prostate center at a major New York City hospital. He put my blood, urine, prostatic fluid, and semen under the microscope, looking for leukocytes and other things of proven irrelevance, and he put me on expensive antibiotics, anti-inflammatories, alpha blockers, and Elavil, an antidepressant given in low doses for chronic pain syndromes. The only certainty was bankruptcy: Prostatitis, he said, was a "frustrating" disease to treat. A third of patients get well, a third show no change, a third get worse.

If women had prostatitis, they'd go on *Oprah*. But men don't like to talk about what goes wrong between their legs. "Guys think there's a stigma," says Mike Hennenfent, president of the Prostatitis Foundation, a patient advocacy group. It's often the wives who contact him. "A minister's wife told me, 'Our congregation wouldn't understand this.'"

Men's silence is reflected in federal spending on the disease, which, until 1995, was practically zero. Prostatitis was the Rodney Dangerfield of urologic conditions, a research backwater and "a wastebasket of clinical ignorance," as one doctor put it. It was thought to be a bacterial infection of the prostate gland, resulting in inflammation. Doctors gave antibiotics, anti-inflammatories, and, beginning in the 1990s, alpha blockers, which help relax the prostate. When this failed, they gave more antibiotics. "My doctor kept upping the dosage to the point where my pharmacist was freaking out," says the Portland lawyer.

"The patient will be given anything that gets him out of the office," says Richard Alexander, M.D., a professor of surgery and urology at the University of Maryland. "That's how the disease is managed."

Hennenfent was a 67-year-old Angus cattle breeder from Illinois who had suffered for 35 years when he helped start the Prostatitis Foundation in 1995 to press for research and serve as an information clearinghouse. Patients organized on its Web site (*prostatitis.org*) and lobbied Congress, which authorized the National Institutes of Health to fund research. Eleven North American academic centers, including Stanford's esteemed urology department, were chosen to conduct research, recruit patients, and run clinical trials. The results are in:

- Prostatitis patients have less bacteria in their semen than men in control groups.
- There is no correlation between the presence or absence of inflammation and symptoms.
- No drug in the pipeline holds promise.
- None of the standard treatments work.

Which is why men end up lying on their backs and learning about paradoxical relaxation.

A 35-YEAR-OLD ACTUARY WAS IN THE FETAL POSITION IN THE EMERGENCY ROOM WITH TESTICULAR PAIN THAT "FELT LIKE I'D BEEN KICKED IN THE NUTS."

Wise, a man of modest height, crinkly eyes, and a long-standing Zen meditation practice, spent 22 years in pain from what felt like a golf ball lodged in his rectum, frequent and urgent urination, and a variety of other distressing, perplexing, and painful symptoms. In 1998, he left San Francisco for Sonoma County, where he lives amid deer and wild turkeys on 11 hilly acres punctuated with a gazebo and nine profusely carved buildings built with his own hands. Wise came to understand that prostatitis is not a disease of the prostate but a kind of ongoing charley horse in the pelvic-floor muscles that surround it—a neuromuscular disorder that strikes men who chronically hold tension in their pelvis much the way TMJ pain strikes those who hold tension in their jaws. For a variety of reasons—anxiety, pelvic trauma, compulsive masturbation or sexual activity, even traumatic toilet training—some men add to the burden of their hardworking pelvic muscles by chronically clenching them. In such predisposed, usually type-A men, Wise believes, a period of intense physical or mental stress can be the final straw, triggering the muscles to constrict. This chronic tension takes on a life of its own, continuing long after any injury or stress abates.

Wise spent a decade learning how to stop the unconscious tightening of his pelvic muscles, eliminating his pain through paradoxical relaxation, certain yogalike stretches, and an eyebrow-raising form of physical therapy based on the concept of trigger-point release. Trigger points are taut bands within muscles, formed through stress, tension, or injury, which radiate pain but can be neutralized by applying pressure. Tim Sawyer, an expert in trigger-point release and a physical therapist, mapped trigger points inside, outside, and around the pelvis that are associated with prostatitis symptoms. »

THE PROSTATITIS ACTION PLAN Take these steps at the first sign of pain

How do you know if you have prostatitis? The most common sign is severe pain in your privates, whether it's the penis, the rectum, or elsewhere in the neighborhood. Some men have climaxes that feel like a leg cramp; others feel as if they have a constant need to urinate. The condition can strike at any age, but most victims are in their thirties or forties, probably because stress appears to contribute to the disorder. While the disease remains poorly understood, here's what you should do, based on the latest and best research:

See a doctor immediately. Some experts believe prostatitis can be triggered by urinary tract infections, in which case treating the infection promptly may be key to recovery. Make sure the doctor cultures your urine; that's the only way to know for sure what you're dealing with.

In some instances, antibiotics will even cure the prostatitis itself, but a large number of prostatitis cases are nonbacterial and must be treated with a variety of options, including alpha-blocker prescriptions and dietary supplements such as quercetin or Prosta-Q.

If you do have an infection and your doctor prescribes an antibiotic, question him thoroughly as to how long you should remain on the drug. If you don't eradicate the infection completely, it could spread and worsen the symptoms. Also ask about muscle relaxants.

Ask for a referral to a urologist, and be sure he's up-to-date on the latest research and treatments for prostatitis. One way to tell: If he doesn't give you the National Institutes of Health patient questionnaire or the Stanford Protocol, he probably isn't on the cutting edge.

Find a physical therapist trained in male pelvic-floor work. One surprising source is the women's health section of the American Physical Therapy Association. Women's doctors have more experience in pelvic-floor work. A list is available at *womenshealthapta.org*.

For more information, go to *pelvicpainhelp.com* (the Stanford Protocol), *urologyhealth.org*, *chronicprostatitis.com*, or *prostatitis.org*. S.R.

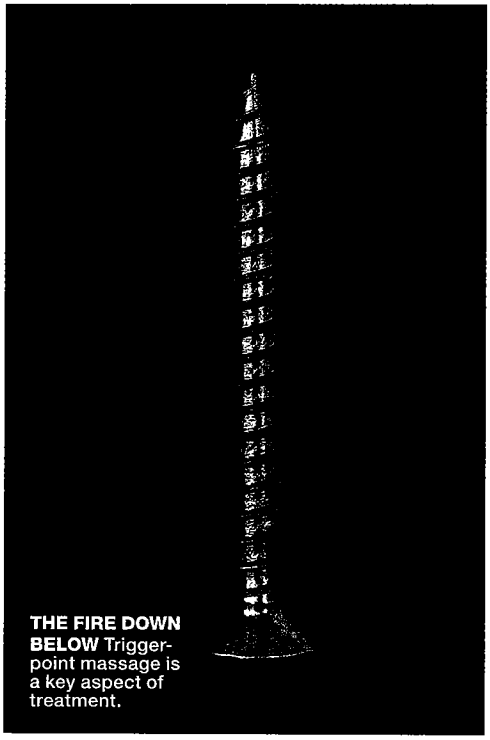
"THE PATIENT WILL BE GIVEN ANYTHING THAT GETS HIM OUT OF THE DOCTOR'S OFFICE."

Wise took his program to Dr. Anderson, a neurourologist at Stanford who was frustrated by his inability to do more for his prostatitis patients. "This is all such a black hole of medicine," says Dr. Anderson. "The doctors just don't get it." The Wise program, he added, is "the best treatment I've seen in more than 25 years of doing this stuff. I have so many patients who say 'Once I started doing this, things just got better.'" In 1995, Wise joined Stanford's urology department as a visiting scholar, and Wise, Dr. Anderson, and Sawyer began seeing patients. Wise and Dr. Anderson published a book in 2003, *A Headache in the Pelvis*, and refined their treatment into the six-day protocol Wise now leads.

Patients finally found relief. "We've gone from a time during which we saw virtually no success stories, to having success stories and recoveries become almost routine," says Mark Meeker, founder of ChronicProstatitis.com. "This is a sea change." In the last 18 months, the treatment's credibility has been enhanced with the publication of two papers in the *Journal of Urology*, the field's leading journal, documenting the protocol's success. The *Urology* articles "really gave hope," says the Portland lawyer, "and a legitimacy the medical community needed."

Back in the lodge, one by one, the men are summoned to an outbuilding for their daily hour of physical therapy, called intrapelvic trigger-point release. With strong fingers, Sawyer works the kinks out of the patient's rectal walls from the inside. Patients' spouses—about half bring theirs—are present during treatment and learn to perform it; the whole point is to teach patients to treat themselves. A tough sell, you'd think, in a culture that dreads digital rectal exams, but these men are desperate and have tried everything from downing boiled broccoli broth morning, noon, and night, to flying to pricey Philippine clinics.

It wasn't until I read *A Headache in the Pelvis* that I fully understood how incompetent my doctors had been. Of course the antibiotics they had given me didn't work—I no longer had an infection. (Patients report that stress worsens symptoms, impossible with an infection.)



THE FIRE DOWN BELOW Trigger-point massage is a key aspect of treatment.

Indeed, the problem with prostatitis is that we don't know whether the prostate is involved at all. (If it were, then why doesn't taking it out—as some men have done, along with having colostomies, anal canals injected with Botox, pelvic nerves dissected, and testicles and bladders removed—cure it?) Benzodiazepines, on the other hand, are designed to treat anxiety and have a second use as muscle relaxants. The other things that helped me—massage and hot baths, which doctors do recommend—soothed sore muscles, not sick glands.

I called Wise, who referred me to Marilyn Freedman, a physical therapist in Great Neck, New York, who specializes in pelvic-floor myofascial trigger-point work. With her South African accent and disarming manner ("I'm very comfortable with rectums!"), she defused the tension inherent in a stranger sticking a finger up your bum.

The days after I saw Freedman were hell. Despite enough Xanax to stun a horse, my symptoms raged uncontrollably for 48 hours. But this was followed, astonishingly, by complete remission—total normalcy for the first time in six months. This faded, alas, after a couple of days, but the flare-up that followed my next treatment was shorter and the state of normalcy lasted longer. Physical therapy released the stress I was carrying around in my pelvis, and I became healthy again.

Nine months later, I was a victim of identity theft, and my symptoms returned. Freedman fixed me in one visit.

Hurdles remain to mainstream acceptance. "Unfortunately, many urologists and pelvic-pain physicians regard trigger points with little more credibility than a Ouiji board," says Wise. Even open-minded doctors face the challenge of administering it in the standard brief office visit, notes Jeannette Potts, M.D., of the Cleveland Clinic, who reached many of the same conclusions as Wise independently and uses trigger-point-release therapy with her pelvic-pain patients.

To doctors taught that prostatitis is a prostate disease, the neuromuscular model could represent a paradigm shift. In this new paradigm, the doctor is a team player: After a physical exam to rule out cancer and other pathologies, the Stanford Protocol integrates physical therapists with the urologists. "It doesn't go over well when a big organization loses a disorder," Leroy Nyberg, Ph.D., the urologist in charge of urology research at the National Institutes of Health, told the audience at a recent NIH-sponsored pelvic-pain conference. Left unsaid was any dread over the loss of 8 percent of urologists' incomes.

Still, the Stanford pedigree, the *Urology* publications, the uselessness of other treatments, and, above all, patient demand are having an impact. These days, physical therapists are nearly as likely as doctors to attend pelvic-pain conferences. Large teaching hospitals have begun using biofeedback for pelvic-muscle relaxation. And the NIH is considering multicenter clinical trials of pelvic-floor physical therapy.

"There has been a groundswell of interest," says Dr. Anderson, who, for the first time, can offer his patients an improved therapy. "It's a whole new ball game." ■

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