

ELLE

OUR
BIGGEST
FASHION
ISSUE...
EVER!

650+
PAGES

COATS,
SHOES,
DRESSES,
BAGS

HAIR & MAKEUP
STEP-BY-STEP GUIDE:
7 EXPERTS
13 NEW LOOKS
46 BEST PRODUCTS
+

YOUR
PRETTIEST HAIR
IN 10 MINUTES
OR LESS

KATE
UPTON

THREW FASHION A CURVEBALL—AND WON

HELLO
SEXY!

SURVIVOR GUILT:
"THEY
KIDNAPPED
HER INSTEAD
OF ME"
A STORY
OF ESCAPE—
AND LEAVING
A WOMAN
BEHIND

BAD AT DATING
WE FOUND A NEW
WAY TO FIX IT—
IF YOU'RE
BRAVE ENOUGH

SEPTEMBER 2013

\$4.99

ELLE.COM



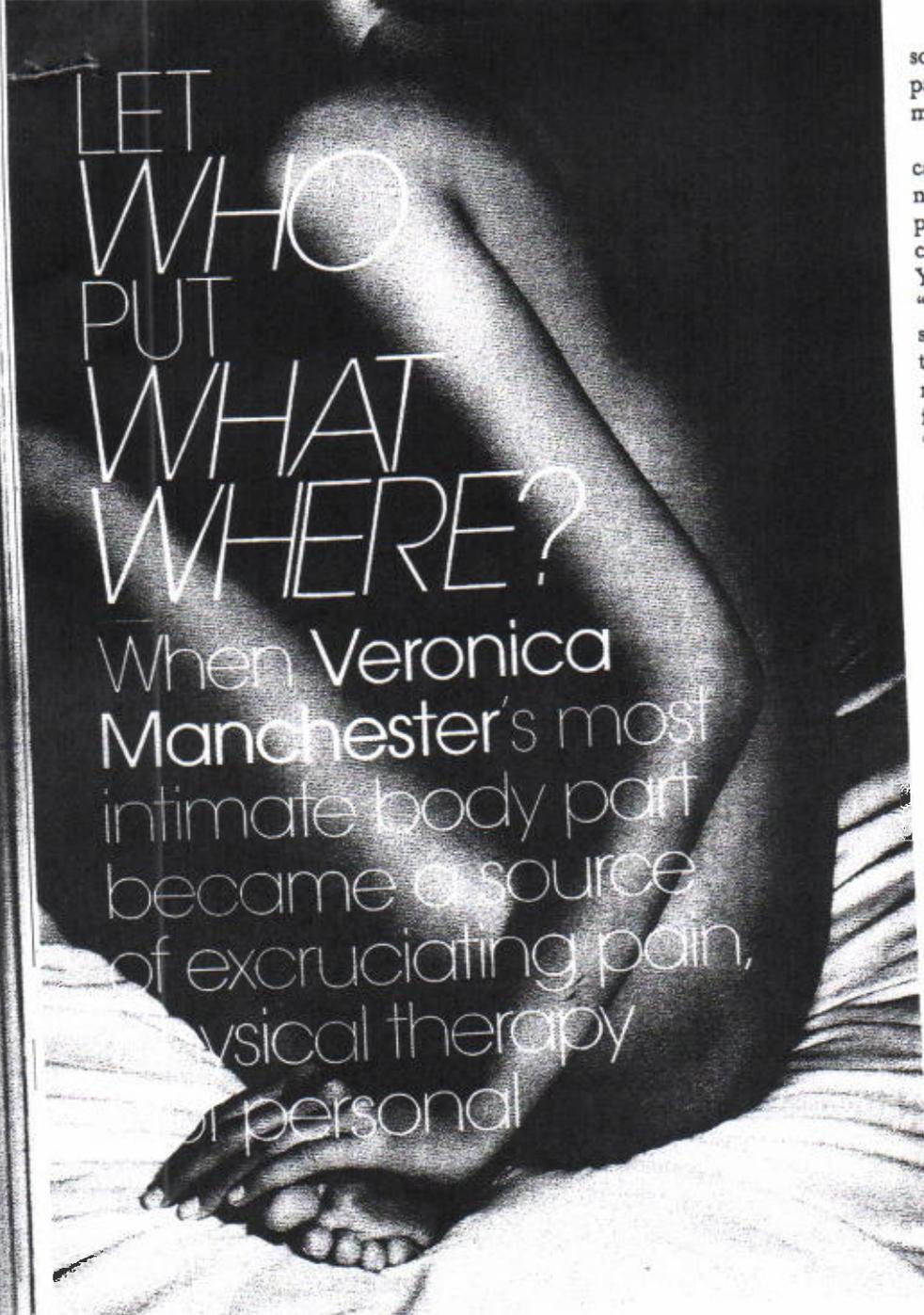
00000

0 279451 0



NEW
CUSTOMIZED FOR
MEDIUM SKIN TONE

DreamTone N°2: Dark Spots, Dullness, Sallowness



LET
WHO
PUT
WHAT
WHERE?

When Veronica Manchester's most intimate body part became a source of excruciating pain, physical therapy or personal

My condition first presented as a harmless, if painful, urinary tract infection. I was on a work getaway in the New England woods, far from my regular doctor, when the symptoms began. "I just need some antibiotics," I told the regional clinic's nurse-practitioner. I'd had many UTIs in the past, I assured her. I knew what they felt like, and they felt exactly like this. Nonetheless, she insisted on testing my urine. She returned to the exam room, perplexed. She'd found no bacteria, she said, but wanted to send my sample to another lab. "If that test also comes back negative, you might have interstitial cystitis." She gave me some handouts about "IC," and refused to write me a prescription for antibiotics

until she received my lab results in two days. *Two days?* Had this woman ever had a UTI? The burning pain, as anyone who has had one knows, impedes your every waking millisecond. Your consciousness relocates to your crotch. A friend of mine—a doctor, in fact—suffered UTI-like burning for months before he had surgery to correct a problem with his urethra. Afterward he told me, "I'd rather cut off one arm than experience that pain again."

Later that night, I looked through the IC information the nurse-practitioner had given me. IC is a chronic inflammation of the bladder wall. No one knows why you get it, and there is no cure or treatment. There is no reliable way—or

sometimes no way at all—to relieve the pain. Do not read those handouts! I admonished myself. You have a UTI!

I did not have a UTI. The culture came back negative. According to the nurse and her pamphlets, all signs were pointing to the cystitis. In a panic, I called my doctor in New York; New York doctors have cures for everything. "You'll just have to ride it out," my GP said when I described my symptoms and the preliminary diagnosis. "If women ruled the world, we might have a cure for interstitial cystitis," he said, sighing. "But they don't."

Happy times. I turned to the Internet for solace. I learned that diet can cause "flares," i.e., more intensely painful episodes. I learned that sex can cause flares (not that sex interested me). I spent the next few days weeping in the woods about all the sex I should have had. Why had I ever claimed I was "too tired"? *What was wrong with me?* I had a perfectly good vagina back then, why hadn't I used it more?

Not that the problem was my vagina. Or, well, not exactly. A week after my first symptoms appeared, I returned to New York City and began the testing hell of "diagnosis by exclusion." IC is a diagnosis you receive by not receiving any other. One by one, my urologist crossed off the alternatives—not kidney stones, not a yeast infection. Soon we were left with just one grim option: bladder cancer. But my bladder-cancer test was more than a week away, and even a day in chronic-pain terms might as well be a decade. I asked my urologist if, in the meantime, I might start some of the treatments she'd suggested I could try to "lower my pain baseline" if I proved to have the condition. One was acupuncture. (You know you're in uncharted medical territory when your Western doctor cites acupuncture as your best pain-relief option.) The other was pelvic-floor physical therapy. She didn't tell me what it entailed; I didn't ask. I was too desperate to be curious.

Which meant that I walked in to my first appointment without the slightest clue what I'd encounter. Would I have to take off my clothes? Yes, I would. Would I have to allow a woman to put her rubber-gloved hand inside my vagina and reach so far into it that I was pretty sure she'd entered a hidden compartment that no longer qualified as "my vagina"? Yes to both. Yes to anything, if it would get me out of pain. Prior to this, I thought of myself as—had even bragged about being—a

Micahela Kostelo

person with a high pain threshold. I'd stoically endured regular migraines for more than 30 years; I'd had two natural childbirths. But this burning around my urethra (and clitoris) stripped me of my identity. I became nothing but a nerve-ending receptor. During my darkest hours, I'd been reduced to scary math. How many years must I live this way? How old must my children be before my suicide won't psychologically destroy them?

While I lay on the exam table, my therapist, Sarah Emmanuel, explained that the pelvic floor is like a braided hammock of muscles suspended beneath your pelvic bone. Because quarters are so close down there—your urethra, your vagina, and your bowel are all near neighbors—the pelvic-floor muscles, when they misbehave, can disrupt the normal functioning of all three.

She conducted a thorough interview involving everything from my reproductive history to my diet to my sleep patterns. She asked me to describe the

vic floor, for which there are a number of possible causes. PFD is a broad category that covers a wide range of conditions such as incontinence, irritable bowel syndrome, and discomfort during sex. My trigger point might have been caused by doing Kegel exercises either obsessively or incorrectly (nope), or a past trauma to the area (not that I could recall), or pregnancy/childbirth (in my case, too long ago to be the culprit), or obesity (no). Trigger points also can be due to stress (bingo). People hold tension in their pelvis, just like they do in their shoulders or back.

My visits to Emmanuel involved a few different treatments. First, she used her hand to massage the muscle from the inside. Then from the outside she massaged my entire right side below my waist. She gave me homework: I had to lie on a hard surface with a tennis ball under my right buttock and do deep-breathing exercises to help me relax, and I needed to pay attention to whether I was holding tension in my

tibiotics and telling you that you have a yeast or a urinary tract infection—if you keep going back, and you keep getting the same answer—it's worth consulting a pelvic-floor physical therapist," she says, then ticks off a list of symptoms that might warrant seeing one, including a diagnosis of irritable bowel syndrome, having to pee all the time (or just feeling like you have to; I was shocked to learn that a person with a healthy bladder should pee only once every two to three hours), or experiencing pain in or around the outside of your vagina just before, during, or after sex.

The therapy has been around only since the late '90s. Stein first encountered the trailblazers of the profession as a physical-therapy graduate student, when the mother of her then boyfriend developed a bladder infection following a hysterectomy. Months later, the woman's bladder and lower-back pain persisted. Stein asked one of her professors what he thought the cause might be.

"My school did problem-based learn-

THE NATIONAL INSTITUTES FOR HEALTH NOTES THAT ONE IN FOUR WOMEN SUFFERS FROM A PELVIC-FLOOR ISSUE AT SOME POINT IN HER LIFE.

pain and where it was located. I still felt the burning, but I'd also developed a terrible, raw ache on the inside right wall of my vagina, almost like a contusion caused by the rough sex I definitely wasn't having. "That doesn't sound like IC," she said of this last symptom. Emmanuel put her hand inside me, touching my hip bone from the inside. She then hooked her fingers under my pelvic bone to access the soft tissue beneath. "That's it!" I said. Using her fingers, she pushed firmly into the spot. I felt as if I'd been temporarily sprung; the sensation was akin to the relief you feel after your tight shoulder muscles are given an almost painfully intense massage. I left her office in a daze. She hadn't confirmed anything, diagnostically speaking, but she had assured me that IC really was very rare.

And after two sessions, Emmanuel was fairly certain I did not have it. (Of all the patients who've come to her with a diagnosis of IC, only one, she believes, really had it; another therapist I spoke with agreed that IC is overdiagnosed by doctors.) What I definitely did have was pelvic-floor dysfunction (PFD) and, more specifically, a "trigger point"—a tight and spasming muscle—in my pel-

vic floor and, if so, release it.

As marginal or strange as pelvic-floor physical therapy might sound, it became clear to me quickly that it shouldn't be viewed as a wacky last-ditch effort to solve a rare problem. The problem, for starters, is common. The National Institutes for Health notes that one in four American women suffers from a pelvic-floor issue at some point in her life. It's also important to understand that the therapy isn't just for postpregnancy incontinence problems. (This was the natural assumption made by friends whom I told about my condition; it was a pleasure to correct them by saying, "Actually, the problem is that my vagina is too tight," even if that wasn't technically true.) According to Amy Stein, author of *Heal Pelvic Pain* and founder of Beyond Basics Physical Therapy in Manhattan (its tagline, "We Go Above and Beyond!," might be more apt if it were, "We Go Below and Beyond!"), more than 90 percent of her patients have the opposite of muscle weakness. Instead, they have muscle tension that impairs bladder and bowel functions and causes sex-related pain or discomfort. "If you have pelvic pain, if your doctor keeps giving you an-

ing," she said. "My professor asked me, 'What do you think it is?'"

Stein laid out her books and concluded, based on the pain's location, that it was related to the muscles in the pelvic floor. She spoke with a urologist, who recommended she consult a therapy group that specialized in pelvic-floor issues. In 2001, she began studying with Holly Herman, who, along with Kathe Wallace—both women are pioneers of the therapy—founded the Herman & Wallace Pelvic Rehabilitation Institute in Seattle. (Stein cites Rhonda Kotarinos as another early advocate—Kotarinos worked in a hospital and witnessed how women were sent home after childbirth with unaddressed pelvic-floor issues, such as sloppy stitching after episiotomies that would lead to excessive scarring and a future life of painful sex.) When Stein graduated, she worked for a sports-orthopedic practice. She started introducing pelvic-floor work and within two years had enough clients to open a dedicated practice.

For many women with pelvic pain, finding treatment is complicated by the fact that the problem is with such a culturally sensitive part of the body. How

many people will you buttonhole about your troublesome vagina in hopes that you'll encounter someone who's had a similar experience? Probably not too many. Also, doctors are not as informed or sensitive as they might be. Let's take my own ob-gyn as an example. Although she's part of a respected Manhattan practice on Central Park West (i.e., a fancy address), she'd never heard of pelvic-floor physical therapy. Assuming I was referring to a treatment for urinary incontinence, she said she sends her patients with "pelvic-floor" problems to urologists. When I asked about issues involving the vagina—painful sex, for example—she said, "Oh, you mean vulvodynia? That's a hard one." (Vulvodynia is excruciating pain in the vulva.) There's no cure, she said; instead doctors try to treat the condition with surgery, nerve cauterization, and drugs. When I told her that she really should look into pelvic-floor physical therapy for her patients, and that many of them might be helped through less-invasive means, she

for months, and the girl was almost ready to have sex with her boyfriend.

Lest you think that vulvodynia is rare, a study published last year in the *American Journal of Obstetrics & Gynecology* found that more than 8 percent of women suffer from it and concluded that the condition "is common, although rarely diagnosed." (By way of comparison, the same percentage of people suffer from asthma—but that number includes women *and* men.) And of course, vulvodynia is only one type of pelvic-floor pain. A 2010 study published in *BMC Family Practice* concluded that "GPs expressed elements of therapeutic nihilism about [pelvic-floor pain]," and "despite practice nurses taking on increasing responsibilities for the management of patients with long term conditions, respondents did not feel that chronic pelvic pain was an area that they were comfortable in managing." It also noted that in 35 percent of women, the preliminary medical diagnoses they receive (endometriosis, for example) aren't con-

After four sessions with Emmanuel, I wasn't quite cured, but I couldn't continue seeing her. I was relocating for the summer to a rural state devoid of pelvic-floor therapists. Emmanuel recommended I buy "the crystal wand"—an S-curved Lucite sex toy designed to help a woman find her G-spot that's been repurposed by pelvic-floor physical therapists. During our final session, she taught me how to hook the toy under my pelvic bone to find my trigger point, which I could knead with the tool's rounded tip. Throughout the summer, that tool saved me. I became skilled at noticing the first signs of a trigger-point attack—a slight urethral pain, which, I realized, I'd experienced frequently in the past and had always before attributed to dehydration (meaning this trigger point had existed, in milder form, for years)—so that I could work at the muscles before the symptoms got worse. And work them I did. I was in the woods again; there was no one there to help me but me.

Now more than a year after my first

I READ COUNTLESS ACCOUNTS BY WOMEN WHO'D BEEN IN DEBILITATING PAIN FOR YEARS, WOMEN WHO KEPT STRICT DIETS AND ABSTAINED FROM SEX BUT WERE BEDRIDDEN NONETHELESS.

said, running out the door, "Interesting, leave the info with my receptionist!"

As Andrew Goldstein, MD, director of Centers for Vulvovaginal Disorders, writes in his foreword to Stein's book, even as recently as the 1990s medical schools didn't consider physical therapy of any kind to be a first line of defense (surgery and medication were the immediate treatments; therapy aided recovery), and ob-gyns in general weren't interested in pelvic-floor issues. Goldstein says that of the 20,000 hours of studying he did as an intern and a resident of obstetrics and gynecology, only one hour was devoted to vulval pain and sexual dysfunction. He also notes that women who suffered pain during sex were thought to be responding psychologically to a past sexual trauma. The problem was not in their vaginas; the problem was in their heads.

Emmanuel told me of a girl suffering from vulvodynia who, despite being unable to have sex or even undergo a routine gynecological exam, was told by doctors for 10 years that the pain was psychological. When I met Emmanuel, she had been working with this patient

firmed by follow-up tests, leading these women back to square one, and into a time- and money-intensive "cycle of re-investigation and re-referral." Doctors, the study pointed out, call women who present with chronic pelvic-pain symptoms "heartsink patients," because this condition is so difficult to treat.

I was fortunate enough to find a urologist who knew about pelvic-floor physical therapy, but even so, her primary focus was on testing. It was only because I pushed that I went to therapy as early as I did.

The good news for people who catch their PFD, however it manifests, early is that a physical therapist can, in many cases and often with just a few visits, make the pain disappear. If a patient has been suffering for years—either because she was ashamed to seek help, or because she figured her urinary condition was a natural function of having kids and getting older—the treatment can take up to a year, and the pain can remain more persistent, even chronic. "You'll have better long-term results before the pain becomes processed by your brain as 'natural,'" Stein said.

symptom appeared, I barely suffer at all. As I'm writing these words, I can feel a vague tightness, but this is because I've been sitting on a hard wooden chair in the library for the past five hours. As Stein says of PFD, "It's similar to chronic back pain. You need to learn your limitations." My limitations are sitting—airplane trips, car rides, long days at the library. Relaxation is key during these times. So is my wand.

During those three weeks when I believed I had IC, I read countless online accounts by women who'd been in debilitating pain for years, women who kept strict diets and abstained from sex but who often were bedridden nonetheless, unable to work and forced to dedicate their lives to managing their suffering. After I discovered that I didn't have IC, I despaired for these women. They number in the hundreds online, and who knows how many more thousands off-line. I couldn't possibly reply to each of them, and so I thought instead that I'd write about it. I hope that many more women can limit their scary pain to just a few weeks, as I did, instead of suffering needlessly for the rest of their lives. ●