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**Our
Pain Is
Invisible.**
**But
We’re
Not.**
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Apart from physical and emotional aches, the most draining thing about living with chronic pain is feeling unheard. Now, a new movement is reframing how we think about, talk about, and treat the debilitating issue that affects millions of women.

By Kristen Mascia | Photographed by Andreas Laszlo Konrath



CONSIDER FOR A MOMENT THE WOMEN in your life who regularly grit their teeth through pain. Your old college roommate who was knocked flat by migraines. The friend who cancels plans because of her nightmarish cramps from fibroids. The running buddy whose relentless backaches have sidelined her from your weekly jogs.

Women are taught that suffering (periods, childbirth, sore joints) is just part of the deal, the crappy door prize we’re born with by virtue of our two X chromosomes. In a way, it is. Chronic pain—the kind that drags on for months or years and throws a wrench into relationships, careers, workouts, and everything in between—affects women in

Kathleen Baker

greater numbers than it does men, and often more severely. Around 56 percent of the 50 million sufferers in America are women.

Yet our medical system is woefully ill-equipped to handle what hurts us. Most of the research has been on men, so many doctors aren't trained to adequately treat the pain-causing disorders that disproportionately touch women, says Maya Dusenbery, author of *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick*. Beyond that, there is the entrenched myth that women's discomfort is all in our heads, says Dusenbery. Yes, even in 2019.

Lump all this together and it's no wonder that women wait longer in emergency rooms than men and are less likely to be given effective painkillers. For women of color—who contend with racial bias on top of sexism—relief is even tougher to come by. Compared with whites, people of color are more frequently not given a pain prescription, according to research.

Left under- or untreated, many women develop ache-amplifying conditions such as anxiety and depression, says Marianne Legato, MD, PhD, founder and director of the Foundation for Gender-Specific Medicine at Columbia University. It's understandable: Being dismissed can make you feel down, so you might not sleep enough or eat well, which can intensify pain.

Attempting to break this vicious cycle is a grassroots crusade of women raising their voices. Hashtags like #PainWarriors and #SpoonieLife ("spoons" are the finite units of energy that people with chronic illnesses must budget throughout the day) are blowing up on social media.

These six women are saying "no more" to the stigma and stereotypes. They're taking command of their care and finding what works for them, on their terms—a lesson for us all.



KATHLEEN BAKER | 22 | TEAM USA BACKSTROKE SWIMMER

Managing Crohn's disease (she was diagnosed with the inflammatory bowel condition at 13) while swimming competitively is a massive challenge. But backstroker Baker has mastered it, nabbing two medals at the Rio Olympic Games in 2016 and turning pro last year. The elite athlete's secret: pushing her body smarter, not harder.

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"Dealing with a condition like this, I've had to learn my limits. It's taken me a long time. My freshman year of college, I pushed too hard, doing too many practices, and got 14th at the NCAA national championships in the 100-meter backstroke. That was a huge lesson: My ability to swim totally hinges on my health.

During a flare, it feels as if someone is stabbing me in the stomach. I can barely move through the water. It's difficult mentally, too, when I know I'm putting in the effort but can't keep the pace in practice. Sometimes I have to lie down in the fetal position. My rule is that if the pain lasts for more than 30 minutes, I'll take myself to the hospital.

Last week I cut down the number of races I'd planned at a meet because I'm just getting back into training. Little sacrifices like that help me stay healthy. So does asking for help when I need it. When I'm able to tell people what I can and can't do, I feel better, and I swim better.

Whenever I stand on the blocks, regardless of how I've been feeling or if I've had bad practices, I remind myself of all the challenges I've pushed through to get there. I tell myself that nothing is going to be as hard as what I've already done, and that I've put in the work and deserve to win.

Knowing the thing you love could be taken away from you at any moment is hard to come to terms with. I try to appreciate what I can do and go into every practice with a smile on my face. Everyone's overcoming something, but *how* you do it is what really defines your character."

Tanika Gray Valbrun

TANIKA GRAY VALBRUN | 41 | FOUNDER, THE WHITE DRESS PROJECT (THEWHITEDRESSPROJECT.ORG)

Fibroids sufferer Valbrun was 34 and eager to discuss her fertility options when an older white male doctor took a quick glance at scans of her uterus and brusquely told her that motherhood wasn't in the cards. Valbrun was stunned at his bedside manner and later wondered

if his approach had something to do with implicit bias, an unconscious set of racial stereotypes doctors sometimes hold without even realizing it. This form of prejudice is why people of color are often undertreated for pain, according to studies. Her experience was one of the reasons Valbrun founded the advocacy group The White Dress Project (the garment is an empowering symbol for fibroids sufferers, who avoid the color because of excessive bleeding). Valbrun transformed from passive patient into proactive power player—and she wants others to know that they can achieve this same mindset shift with these steps.

VALUE YOUR HEALTH

“Make it as important as your job, your family, and your relationships. In my 20s, I was just focused on career, career, career. I didn't want to take time off for surgery and miss out on opportunities. If I could do it all over again, I would've done more research on fibroids and asked how they might impact my fertility.”

LEAN ON OTHERS

“Build a team of health champions who can support you in different ways. Two of my close friends are doctors who sorted through options with me before my second surgery, which one of them performed. My husband is an attorney who helps me make health decisions logically. My mom is just my mom; she prays with me and takes away some of the burden.”

BELIEVE YOU ARE WORTHY

“As patients, we have the right to choose the doctors who best respond to our needs. Over the past few years, I've primarily selected physicians who are women of color and who've had experience working with patients whose cases are complex like mine. I know finding a new provider is hard—calling insurance, filling out new paperwork, getting new scans. But if you're not being heard, it's necessary.”



PO ROCHISTA



ON KHAKPOUR: C/MEG COLLECTIVE DRESS; ON VERNIA: AMERICAN EAGLE TOP, CITIZENS OF HUMANITY JEANS

KHAKPOUR

**POROCHISTA KHAKPOUR | 41 |
AUTHOR OF SICK**

Dating with chronic pain is complicated, says Khakpour, author of the acclaimed memoir *Sick*. She would know. The writer, whose Lyme disease relapses include symptoms such as bone-deep fatigue and muscle aches, has had to say “thank u, next” to men who couldn’t hack the realities of her illness. Here, why she hasn’t given up on love—and her true feelings about guys with white-knight complexes.

WHAT’S DIFFERENT ABOUT BEING IN A RELATIONSHIP WHEN YOU’RE DEALING WITH CHRONIC PAIN?

PK: When you’re the partner of someone who’s not well, you need patience, a certain bandwidth. I’m needier when I’m ill. I literally need things—rides to appointments, help making meals. But that doesn’t mean I’m looking for someone to save me. I’ve also had the experience where, when ill, my DMs are filled with guys who want to fix broken birds. I think they find it titillating, or a challenge: *Here’s a woman who’s fragile—how can I solve this problem?*

WHICH IS IRONIC, BECAUSE SOME OF YOUR EXES STRUGGLED TO COPE WHEN YOUR SYMPTOMS FLARED.

Right. My theory is that my illness made them think of the inevitability of their own life—that eventually, everyone’s body breaks down. I was in a relationship last fall, and when I went to the ER, my boyfriend entered a place of fear and soon broke up with me. It’s not just men—I had a close friend tell me that my situation scared her. She almost felt as if she were going to get sick herself if she spent too much time thinking about me.

WHAT HAS YOUR ILLNESS TAUGHT YOU ABOUT BEING A PARTNER?

I’ve become more of a good nurturer, even while sick. I think I am empathetic, caring, and loyal. I’ve said that I’d like to go out with someone who also has a chronic illness. My friends think it’s a terrible idea. “Who’s going to take care of you guys?” they say. But that doesn’t worry me. I like sharing things—like healing together! And taking care of things. I’ve never killed a plant in my life!



Kerri
Verna

KERRI VERNA | 44 | YOGA INSTRUCTOR

Fifteen years ago, Verna took her first yoga class. The pain from her fibromyalgia, a disorder that causes her “muscles and joints to feel bruised and too sensitive to be touched,” was at an all-time high. After one class, she was hooked. Today, she’s a yoga instructor with a million followers watching—and commenting on—her every body-twisting move on her Instagram, @Beachyogagirl. Her goals: to show that change is possible and that relief from chronic pain is not elusive.

“I started sharing my yoga on Instagram six years ago. Over time I began mentioning my fibromyalgia, though it’s not always easy. I inevitably receive unwanted ‘advice.’ *Have you tried this?* people will say. Some commenters argue with me about my symptoms or tell me fibro is not a disease at all.

Still, I keep posting because I know that for every person who dismisses my condition, there’s another who discovers support in my openness. Many of us with fibro find it’s easier to smile than explain why we’re not feeling good. But it’s toxic to allow others’ opinions to make you feel guilty or ashamed for living with a chronic illness.

A lot of people who follow me on social are discouraged by their pain. No one understands, they say; they don’t know where to turn. I always tell them, ‘I get it.’ Two years ago, after I taught a yoga class in England, a man told me his teenage daughter had to give up dancing after she was diagnosed with fibro. She was depressed and suicidal, but then she found my Instagram, began practicing yoga, and now feels so much better. It was a powerful moment; I had no idea I was making that kind of an impact. I used to feel very woe-is-me about my fibro, like a victim. But now I see it as a blessing. It keeps me grounded and makes me grateful for everything I can do.”

Abby Norman

ABBY NORMAN | 28 |
AUTHOR OF ASK ME ABOUT MY UTERUS

That dismissed-by-doctors feeling? Norman knows it well. She was 19 when she doubled over in the shower with lacerating abdominal cramps. Since learning she has endometriosis, the writer has had more than one run-in with a dubious MD. What she's learned: You can't determine how doctors approach chronic pain, but when you control your own story—using these strategies—they're more likely to listen.

PRACTICE

Rehearse articulating your symptoms clearly and succinctly (a task that can be hard when you feel sick or intimidated). Bring notes to the appointment—or even better, a trusted plus-one who can offer support and keep you focused. If a loved one can't fulfill this role, consider finding a health advocate through your hospital or health-care system. Some churches and community health centers also offer volunteers who can help.

BRING RECORDS

Request physical copies of test results, doctors' notes, imaging scans, and surgery write-ups and keep them with you (or make sure you can access them on your phone). This advice is especially important if you're seeing a doctor in a different health-care system, state, or country.

BE SPECIFIC

The more details you can give about your pain—where it is, how it feels (burning? aching?), positions or

activities that make it better or worse, how long it's lasted, how it impairs your function or interferes with daily tasks—the better a doctor will be able to assess it and pinpoint its cause. "I have abdominal pain" is vague. "I have pelvic pain that's worse when I have sex or a bowel movement" will help them narrow it down.

LEAVE ON FIRM FOOTING

Before you walk out the door, rehash with your doctor, out loud, what you've discussed. Explain what you heard and your understanding of what was discussed. You aren't just repeating what they said like a parrot; you're giving them a chance to clarify, ensuring you're on the same page.



GAYLYN HENDERSON | 34 | FOUNDER OF GUTLESS AND GLAMOROUS (GUTLESSANDGLAMOROUS.ORG)

At 14, Henderson was diagnosed with Crohn's disease, which can cause devastating abdominal pain. After a few years of failed treatments and medications, her doctor suggested she have an ostomy, an opening connected to a plastic pouch worn outside the body that collects waste directly from the intestines. She wept, imagining how it would limit her life. In a letter to her younger self, Henderson—who writes about her illness on her website and on Instagram (@Gutlessandglamorous)—shares the greatest lesson she's drawn from her years-long struggle with self-image.

Dear Gaylyn,

So it's done. It's in. The surgery is over. You can look down now. As a matter of fact, take a long, hard look, because this is going to change your life for the better.

I know you were hesitant about receiving an ostomy. You're afraid you'll be an outcast; that you'll never be able to wear a bikini again; that you'll never find love, or even love yourself again.

I promise, you will have all those things. But it's going to be a process. So don't let society's views of beauty dictate how you view yourself. Your scars make you victorious. Unique. More than beautiful.

Feel the hurt, feel the pain, feel the fear. They will help mold you into the woman you're meant to be. Every day, when you look in the mirror, let your ostomy remind you of how strong you are. Use this strength to acknowledge the light within you. Hold your head up high. It will get better.

Gaylyn Henderson



Natural Pain Killers

One of chronic pain's nastiest qualities is that it's compounding. "The brain is hardwired to focus on pain," says Stanford University School of Medicine pain researcher Beth Darnall, PhD. And a steady diet of *ouch* conditions the mind to become extra sensitive to it—which feeds existing discomfort and also primes you to feel even more of it in the future.

That's why the most effective treatment plans blend physical and psychological therapy to soothe the nervous system. For example, a patient might be coached to reduce stressors (by, say, breaking off toxic relationships), exercise, get enough sleep, and practice mindfulness. These individually tailored comprehensive plans have proved to be better than possibly addictive pill-centric pain management.

Each patient is unique, with a different pain history and distinct needs, so talk to your physician about the best mix of tools for you. There's no quick fix for chronic pain, Darnall says, and no one-size-fits-all solution. But there is one that's just right for you.

STYLING: ANN WANG, HAIR: CHARLES MCNAIR AT SEE MANAGEMENT USING ORIBE, MAKEUP: SARAH APPELEY USING GLOSSIER, MANICURE: JINI LIM AT SEE MANAGEMENT USING CHANEL LE VERNIS, ON NORMAN; GUESS JACKET, EVA MENDES COLLECTION AT NEW YORK & COMPANY, SWEATER, ON HENDERSON; SNIDEL DRESS