

Women's Health

6
SECRETS
FROM THE
ABS
WHISPERER

⚡
THE
OWNING IT
ISSUE

Make
Vulnerability
Your
Superpower ✨

LONGEST.
LASHES.
EVER. (SWEAR!)

ROSARIO
DAWSON
ON HEALTHY
RELATIONSHIPS
WITH FOOD, HER
PARTNER, AND MORE

COOK
ONCE,
EAT
CLEAN
ALL
WEEK

Get
That
Glow

GYM MAKEUP +
SHINY HAIR +
HAPPY SKIN +

ON THE COVER



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EAT CLEAN ALL WEEK**
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Owning It

After being put through the health-care wringer, eight women with complicated, often-stigmatized conditions open up about how they're fighting back against misconceptions and taking charge of their own narratives.

By Allison Goldman



ILLUSTRATED
BY
**Amelia
Butlin**

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about Amelia on
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Being sick sucks.

But what's worse is not knowing the reason you feel crappy. Finding a diagnosis for some conditions can mean traveling from doctor to doctor and enduring a slew of tests, some of which may be uncomfortable and invasive. Negative results can mean starting back at square one—a new guess at what the illness might be, a new set of providers, and even more poking and prodding—like the world's worst game of Chutes and Ladders.

Most of the people experiencing this confusing health-care back-and-forth are women—who are more likely to suffer from hard-to-diagnose conditions ranging from fibromyalgia and autoimmune diseases to reproductive issues like endometriosis and polycystic ovary syndrome

(PCOS). Scientific research has historically excluded women, which piles onto the problem, explains Alyson J. McGregor, MD, cofounder and director of the Division of Sex and Gender in Emergency Medicine at Brown University and author of the forthcoming

book *Sex Matters: How Male-Centric Medicine Endangers Women's Health and What Women Can Do About It*.

If and when a diagnosis does come? Depending on what that "label" is, a woman may face a barrage of unique biases. Women are described in studies as more sensitive to pain than men, and women with pain are perceived as more emotional. (Or, you know, maybe we're just on our periods! Eye roll.)

The women here—who represent a spectrum of hard-to-diagnose or underrepresented conditions—can all speak firsthand about these obstacles. But they also know what it's like to confront the frustration and misperceptions head-on in order to control their own stories. As Pame Clynes, one of the powerhouse ladies you're about to meet, puts it: "Let's break the silence. Let's do it together. And let's advocate for your condition."

"LET'S DISPEL THE MYTH THAT ONLY SMOKERS GET LUNG CANCER."



MONTESSA LEE, 41

DOCTORS misdiagnosed me twice before figuring out I had small-cell lung cancer. I finally got an X-ray after I went to the ER for coughing and stabbing chest pain, and they discovered a tumor the size of a cantaloupe covering three-fourths of my lung. It was 2006, and I was 28 years old. I was also a nonsmoker—something I tell people along with my diagnosis, because I know they're going to ask.

When my oncologist first told me I had small-cell lung cancer, I looked it up and learned the five-year survival rate was 7 percent. I had to take time off from my job as a special-education teacher during my treatment because of the high levels of chemo and chest radiation I was receiving, as well as the resulting fatigue I had to deal with. I had nothing to do during chemo and radiation, so I sent

messages to legislators, asking for research funding. I went to a lung cancer research summit in 2008 and started networking and speaking on panels.

At first, I did all of this because I was mad. I wanted others to know that young people who are not smokers can be diagnosed with lung cancer and deserve research to help improve the outlook. Then, when I learned that cancer is deadlier for African Americans, I was angry about that too. Overall, about 161 people out of 100,000 die of cancer each year. But for African Americans, that rate is 185.6, higher than for any other race.

A lot of the disparity has to do with health-care access, and I've recently started to talk about this more with people I know. Patients should be getting the same care wherever they go, whoever they are.



"PAINFUL PERIODS ARE NOT THE NORM."

I remember being 18 and missing college classes because of my heavy periods. My cramps were so bad I would be nonfunctional for a day or two. When I complained, doctors would usually tell me something like, "Oh, that's what a period is."

In February 2012, after at least four other appointments over the years



AZMIA MAGANE, 34

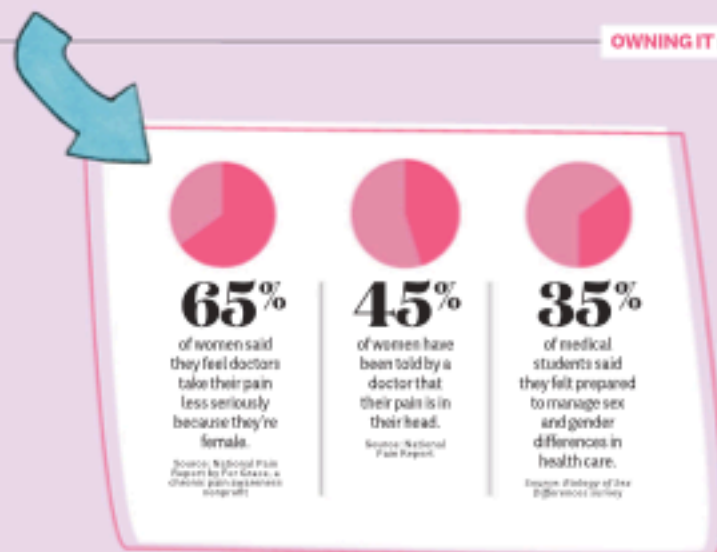
with gynos who dismissed my symptoms, I underwent a surgical procedure called a laparoscopy, which is used to look at the outside of the uterus, ovaries, and other organs. When I woke up, the doctor told me there was nothing wrong with me, that maybe I was depressed. So I sought another opinion.

The new doctor really listened to my symptoms and said he thought I had endometriosis, a condition in which tissue grows outside of the uterus, causing symptoms like pelvic pain, bleeding, and cramping. He repeated the laparoscopy and then told me my insides were fused together; I had stage-4 endometriosis.

For the past decade or so, in addition to working in child welfare, I've been writing about women's health and other issues that affect the Muslim community. Writing is a form of activism for me.

I hope my experience can keep someone else from having to go through the endo hell that I have endured.

“THE PCOS CONVERSATION NEEDS TO CHANGE.”



“WE HOST A PODCAST ABOUT LIVING WITH TYPE 1 DIABETES.”



LAURAE BURNS, 37

I'D EXPERIENCED irregular periods, rapid weight gain for no apparent reason, and extreme difficulty losing weight since I was a teenager. But I didn't see a doctor about these issues for years. I'd had a lot of negative encounters with providers who said things like they wouldn't take me as a patient since I was above their weight threshold. I didn't think it was worth the time or trauma to try.

When I finally sought medical help about two and a half years ago because I couldn't ignore my symptoms anymore, I was diagnosed with polycystic ovary syndrome, a condition in which an imbalance of reproductive hormones causes ovarian cysts, irregular periods, body hair growth, and more.

The doctor said something like, “You should try to lose some weight,” and sent me on my way. Even though weight loss doesn't resolve PCOS—there is no cure—I've spoken with a lot of other people who, unfortunately, say they've had experiences similar to mine.

As a result, social media posts about the condition often focus on dieting. But as someone who is in recovery for binge eating

disorder, that type of messaging was triggering for me. So I started talking about PCOS online to change the conversation.

After my diagnosis, I began posting videos on YouTube about what I go through with PCOS, and also using PCOS-related hashtags on Instagram to start a community that doesn't push weight loss and body shaming. And since I'm a yoga teacher and body-liberation coach, something I've been doing for about five years, I posted a video on YouTube about yoga specifically for people with PCOS, and I plan to add guided meditations.

I try to talk candidly about how the condition impacts my life so other people can be open and honest too. My one little voice is not going to make this entire world less fatphobic—hopefully, we'll get there in time—but I hope it can convince someone to see a professional sooner. I'm definitely glad I finally chose to go to a doctor, even if it wasn't a perfect experience. Now I have an actual diagnosis, medication, and someone to help me figure out how to care for my body.

We were diagnosed with type 1 diabetes at very different times in our lives: One of us [Miriam] was 6, whereas the other [Emily] had almost two beautiful decades with a working pancreas before an autoimmune reaction caused it to stop producing insulin. Still, our experiences have been similar in so many ways.

When we first got a label for our chronic illness, no one really talked to either of us about how it was going to change our



EMILY GOLDMAN, 26, AND MIRIAM BRAND SCHULBERG, 30

lives emotionally, socially, and psychologically. We always felt there was a void there. That's a big part of why Miriam became a mental health counselor—and it's why we cohost our podcast, *Pancreas Pals*, together.

Diabetes is a challenge, and people are often insensitive to our needs in surprising ways—like when airport staff are jerks about the fact that we have to carry medical supplies on planes. We shouldn't have to advocate for ourselves in situations

like that, but we do because no one else is doing it for us. And that's what our podcast is all about: advocating for yourself and helping others with type 1 diabetes realize that educating people about the disease doesn't have to mean giving a formal presentation to all your friends. Instead, you do it by sharing bits and pieces of what it's like to live with your condition.

"I STRUGGLE WITH MY SCHIZOPHRENIA OUT IN THE OPEN."

TOWARD the end of high school, I discovered something called a pulsar—a type of neutron star—with another student. I also helped represent the United States in the International Space Olympics in Russia and attended a program at NASA. At the same time, symptoms I'd had for a while—like hearing and feeling things that weren't there, such as voices and shadowy figures—became more pronounced.

I felt as if I were losing my mind—and my future. I worried that if my symptoms continued to get worse, I wouldn't be able to succeed in college or even just function. I didn't want a mental health diagnosis to embarrass my family, either, so I decided not to talk to a doctor about it. It was all too much to deal with, so I attempted suicide my freshman

year at Penn State. It was a difficult time for me, but I got through it.

Eight months later, I was having dark thoughts again. At that point, though, I had started opening up to some friends about what I was going through. They supported me, believed I had a medical condition that could be treated, and gave me the courage to finally seek help. That's how I got a diagnosis of schizophrenia.

I didn't know at the time if treatment would help, but now I know that it definitely does. My college was beyond supportive too; I was allowed to reduce my class load and take some courses that were a little less stressful.

I feel so lucky to have met people who've been positive and understanding about my diagno-



CECILIA MCGOUGH, 25

sis—so I founded the organization Students With Psychosis around a year ago to help ensure that others experiencing these kinds of mental health issues have a similarly supportive community. Last fall was our first semester expanding outside of Penn State, and we now have more than 60 student leaders across the world who are interested in getting involved at their schools.

Among my favorite outreach events are our silent discos, where everyone dances but has headphones on and is listening to their own music. It's really fun, and it also helps spread awareness about audio hallucinations, which can occur with schizophrenia. What I've finally realized is that hiding my condition doesn't help anyone—but speaking out does.

MEET THE ILLUSTRATOR

Amelia Butlin

Amelia is an artist with fibromyalgia. Much of her work focuses on how the medical community dismisses health problems that primarily affect women. Find her on Instagram @cantgoout_imick.

Speak Up

When dealing with your health issues, you want your doc to really hear you—but it can be intimidating to speak up or push back on a professional opinion. "It becomes very difficult to trust yourself when an expert in a white coat who's been to medical school for years is saying that your own experience of your body is not accurate," says journalist Maya Dusenbery, author of *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick*.

We asked Dusenbery what to say to get your doc to listen. And if you still don't leave satisfied, don't be afraid to seek out a second opinion, "or as many opinions as it takes to get the right diagnosis," Dusenbery says.

IF YOUR PROVIDER SAYS
"That's normal."

FOLLOW UP WITH
"This may be normal for someone else, but I know what's normal for me, and this is not something I've experienced before."

For example, if a doctor tells you it could just be stress, Dusenbery suggests explaining what stress typically looks like in your body and how these symptoms are different from that.

IF YOUR PROVIDER SAYS
"We don't need to test for that."

FOLLOW UP WITH
"How did you arrive at that conclusion?"

This one is tricky, admits Dusenbery, because medical overtesting is a real issue. That said, you are most definitely entitled to ask your doc to explain their reasoning.

IF YOUR PROVIDER SAYS
"Maybe you're just not getting enough sleep/exercise/etc."

FOLLOW UP WITH

"This is how my symptoms are functionally impacting my life." Dusenbery says it's harder for doctors to disregard how a symptom like fatigue or pain is objectively affecting you versus how it's making you feel subjectively. So if you are too tired to walk your dog or take a shower, say that explicitly.

IF YOUR PROVIDER SAYS
"Let's give it some time."

FOLLOW UP WITH

"Here's when I started experiencing the problem, and here's how it's progressed since." The idea, says Dusenbery, is to emphasize that you feel you've already waited and still haven't improved (or maybe have even gotten worse), to encourage your doctor to deal with the problem now, not in a few weeks.

"TALKING ABOUT VULVAR PAIN SHOULDN'T BE TABOO."

A few years ago, my post-work ritual looked like this: rush home, rip off my jeans and underpants, and ice my vaginal area. That was the only thing that helped with the burning pain I felt down there.

I was working on a master's in fashion marketing and interning in New York City when I first started experiencing these issues,

but I eventually moved back home to Mexico City, where I continued to try to get help. I was lonely in NYC, plus there was always a bit of a language barrier, so it made sense for me to deal with my health in my home country. No one there could tell me what was wrong, though. Most of the doctors I saw were men, and

they often suggested therapy, implying that I had experienced sexual trauma.

In 2015, I was rewatching an episode of *Sex and the City* that mentioned vulvodynia, the term for chronic pain in the vaginal area for which you can't pinpoint a cause. I Googled it and found the National Vulvodynia Association website, and

I was like, "This is what I have." I saw specialists in the Miami area, where my dad lived, and in 2016, a gyno confirmed I had vulvodynia and pelvic-floor dysfunction.

I tried a bunch of treatments: nerve blockers, pelvic-floor therapy, other medications, acupuncture. Some worked and some didn't. But the big-

gest lesson I learned is that knowledge about your condition is power.

My pelvic-floor physical therapist in Miami asked me what it was like to be treated for vulvodynia in Mexico, and after hearing about my experiences, he pushed me to start advocacy work. In my culture, it's taboo to talk about conditions like vulvodynia,

so there's not a ton of info or support available.

To help address this, I created the social media account @peacewithpain and posted information about vulvodynia in Spanish to make it accessible to more women. Two years later, the account has more than 30,000 followers—and we won't let shame silence us.



PAME CLYNES, 36

"MY FIBROMYALGIA INSPIRED ME TO BECOME A TRAVEL BLOGGER."



SARAH
KIM, 32

I N MY EARLY 20s

I was a CPA in New York. I really hated my job, and I was always just going, going, going.

Then, in December 2012, I began feeling a stabbing sensation that went from my lower back all the way down to my left foot. The nerve pain spread all over my body, even in my face, and I began having chronic muscle tension, cystic acne, and bad digestion issues.

I went through a ton of tests, and everything was ruled out: arthritis, diabetes, heavy metal poisoning. It was a couple of years before a doctor even mentioned fibromyalgia. People who have it have often gone down similar paths of being

tested for other conditions and then informed they have fibromyalgia when nothing else comes up positive.

I was in so much pain, and I was irritable and overworked. I thought, *This is the time to move and try something new.* My now-husband and I were engaged at the time, and I asked him to request that his company relocate us. But when they moved us to Amsterdam in 2015, I was on the couch for 8 to 10 hours a day, and I depended solely on my husband, both financially and physically. My hands hurt so badly that I couldn't do the dishes. I'd leave the door open when I took a bath, in case I needed to call

for him to help me climb out of the tub.

I needed to figure out what I could do from the couch. So I started blogging, and that's how my travel blog, *Least 'Till Dawn*, came to life. Now I wake up and look forward to working. When I'm not feeling well but need to take photos for a client, I push myself to get out there and do it. If it weren't for the blog, I wouldn't know I was capable of that, but I am.

I've also been going through a lot of therapies in the past four years, and this year, I finally found a group of doctors who work well for me. I can see the difference: When I went to Lisbon in 2016, I took a ton of Ubers. Now, I can walk.