



Switching Channels

A decade ago, Shireen Sandoval was living a charmed life with a dream job on television. Then a rare illness threatened to take it all away.

By Shireen Sandoval, as told to Beth Johnson

GROWING UP IN NEW MEXICO, I WAS ALWAYS INVOLVED IN SPORTS AND I ESPECIALLY LOVED TO RUN. When I was 8, I started biking alongside my dad when he took long runs; by the time I was 12, I was a runner, too. I started regularly entering half and then full marathons around the Santa Fe and Albuquerque area.

BIG DREAMING By the time I was in high school, I was dreaming of becoming the next Katie Couric or Diane Sawyer. So after graduating with a degree in broadcast journalism and theater arts from the University of New Mexico, I took my first job as a beat reporter in Amarillo, TX. From there, I moved around the country for my career; along the way, I moved into on-air entertainment journalism. The one constant in my life was running. It always cleared my head from the stress of deadlines—and helped me look good for the camera!

When a Miami station came knocking in 2002, I was very excited. I started working for WSVN Channel 7's entertainment news show, *Deco Drive*. Soon I was interviewing some of the biggest names in movies and television, including Oprah Winfrey and George Clooney. I also love showing audiences all of the fabulous and fun things that Miami has to offer. Except for a two-year break when I took a job in New York City, I've been here ever since.

COMING UNDONE

Then in 2010, my life changed profoundly. I had just returned to Miami and *Deco Drive* with an additional job title—film critic. I was in heaven. I had an apartment on the beach, where I ran daily, and I had a great job working with people I really liked.

Then suddenly I started feeling incredibly fatigued and depleted. I was a Type-A, high-energy person—I didn't have time to be exhausted! I also started experiencing tingling and numbness in my feet. I was a shoe addict—my collection rivaled Carrie's in *Sex and the City*—and now it hurt like crazy to even put them on. My lower back also inexplicably began aching. But then came a moment when I knew something was seriously wrong and that absolutely terrified me: I was walking with a load of laundry, and my legs literally stopped working. At that same instant, I was hit with excruciating lower back pain. It was as if someone had smashed my lower back with a baseball bat. I fell to my knees wailing like a wounded animal. It still makes me emotional thinking about it.

SEARCHING FOR AN ANSWER

I visited every doctor who was recommended to me, but the pain kept getting worse. It was as if my body was on fire. Doctors figured it was some kind of virus, but none of the treatments they tried worked. Over the next few months, the tingling and numbness progressed from my fingers up into

PREVIOUS PAGE: WORKING ON MERMAID STRETCH WITH GRETCHEN WAGONER AT BREATHE PILATES

THIS PAGE, TOP TO BOTTOM: BACK IN THE SWING OF THINGS, IN PLAYA DEL CARMEN, MEXICO, 2019; ON THE JOB.



my elbows, from my toes up into my knees, and then up into my hamstrings and my quads. The pain, meanwhile, would start at my calf, wrap around my knee, then

go around the back of my leg and up into the central part of my back.

It got to the point where I couldn't walk. I couldn't use my hands. I couldn't sit up straight. It was physically and emotionally devastating. In just a matter of months, I went from running on the beach and looking glamorous on camera to being bent over a walker. I kept searching for answers because I knew that if I didn't, I was going to die. I went to voodoo doctors, I went to healers, I went to anyone who might help me. None of it worked.

MAYO CLINIC AND A DIAGNOSIS

After six months, I finally got a break and scored an appointment at the Mayo Clinic in Minnesota. I met with a team of six specialists and within 20 minutes, I had a diagnosis: I had a chronic version of Guillain-Barre

syndrome, a rare and potentially crippling disorder in which your body's immune system attacks your nerves. Specifically, I have what they call CIDP—chronic inflammatory demyelinating polyneuropathy, which meant that the sheaths that encase the nerve endings—the myelin—were damaged and misfiring. Though some people recover on their own, others may have many flare-ups with just partial recovery in between.

SOME RELIEF

After the diagnosis, I was connected to a neuroscientist in Miami who mapped out a treatment plan for me. Every other month for the next year, I went through IVIG (intravenous immunoglobulin) treatment—an intense three-day, six-hours-a-day infusion. Thankfully, IVIG helped me a lot.

It took away the truly excruciating pain and it got me past the horrible muscle weakness. I was able to stop using a walker after the third treatment, but it also left me exhausted and nauseous. I had gone to PT for years but I was still fragile and still experienced relapses.

SUPPORT FROM COWORKERS

At work at Channel 7, my colleagues and bosses were incredibly kind and supportive. It was obvious something was wrong with me—I was skeletal and bent over. I tried to hide it as best I could, and I'd rally for the camera. Whatever I needed, though, they would help me. When I needed time off to be infused, I got it.

Still, I didn't want to be "the sick girl." I also found it difficult to manage my expectations. In my mind, despite all that I'd been through, I was

still convinced I was going to get better if I just pushed through the pain. I'm very driven to succeed, and I had to remind myself to slow down all of the time.

MANAGING MY PAIN

Here's the catch with CIDP: if you don't exercise, you hurt. If you exercise too much, you hurt. I tried running again, but it was too painful. I couldn't take any pounding on my joints or lower back.

So I managed it the best I could, but I'd end up in these pain cycles that I call episodes. If I was too stressed out, too run down or tired, or when I tried to go back to running, I would experience a flare-up and end up with debilitating, flat-on-my-back-in-bed agony.

DOCTOR'S ORDERS

After six years of dealing with the pain, fatigue

and limitations, I was very depressed. I was so tired of being a patient. I mourned for the person I used to be. I missed being able to take a run to feel better. I was tired of having track marks in my arms from all the medications and treatments I'd taken. I looked malnourished and twice my age. I was always lean, but since getting sick, I'd lost nearly 30 pounds—I'm 5'8" and I barely weighed 90 pounds. It's hard to want to eat when you're feeling lousy.

I dreamed of being the super-active person I had once been, and then would get so sad thinking about it. Many days it was pure willpower that got me through. My doctor had been nudging me to find a way to exercise, but I was afraid I would have a flare-up. Then one day he said, "I heard of this woman named Gretchen Wagoner. She has a Pilates studio, and

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she has studied how to help people with neurological issues." I agreed to go, though at most I thought maybe she could help me to walk a little better. I certainly kept my expectations in check.

FINDING PILATES

The first time I walked into Breathe Pilates, in Miami's MiMo district, I was so fragile. I was limping from knee surgery, and my shoulders and chest were hunched because I was trying to guard myself against pain. I felt like I was in a shell of a body. I was still struggling just to get through the day. I was trying not to give up, but I was losing hope

that I'd get better. But everything began to change from that moment on.

In that first private session with Gretchen, we just did gentle stretching, articulating the spine and opening up my chest. After that, I had one private a week and I felt better after each class—and no flare-up happened afterward. It was the first time in six years where my body didn't punish me for exercising. It gave me such hope.

Since I couldn't feel my feet or my hands, Gretchen modified movements and ordered equipment that could help me. She put texturized mats down so my feet could feel them

ABOVE: TAKING ON TEASER

HEADSHOT BY TODD PHILLIP PHOTOGRAPHY; OTHER PHOTOS BY JAMES WOODLEY PHOTOGRAPHY



THIS PAGE, LEFT TO RIGHT: PARIS, HERE I AM! CELEBRATING A RETURN TO LIFE IN THE CITY OF LIGHTS, 2019; AT THE PODIUM, HOSTING STATION WSVN'S ANNUAL WINTERFEST GALA, 2018

OPPOSITE PAGE: GRETCHEN HELPS SHIREEN WITH LATERAL FLEXION

better. Since my illness causes poor circulation in my extremities—when I grasp something for more than 15 seconds, my hands go completely red and then they go white—Gretchen added bands that made it easier for me to pull. Even when I wasn't at the studio, Gretchen would help me. She studied up on my illness. She'd send me YouTube videos about Joseph Pilates. She became a collaborator to help me become physically capable again.

Doctors think that the virus started in my spine, and that's where

I still have the most weakness and damage. The hardest thing for me to do is a Roll-Up. But I love doing Teaser because it makes me feel so good about myself. I can't do it for very long, but when I do it, I think, "Look how far you've come!"

ON-CAMERA SUPPORT

Not only did Pilates start helping me so much physically, but it also assisted me on the job. I've been doing television for over 20 years and Gretchen taught me about breathing through

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things and opening my chest to help my posture. I'm 100 percent more connected to my body now. There have been moments when I would be in such pain before going on air. Now I use the breathing exercises that Gretchen taught me.

Learning body awareness through Pilates has been invaluable in helping me deal with chronic pain. My nature is to go, go, go, go, go, but my body can't do that without having a flare-up and feeling worse. I have had to learn to manage my expectations and pay attention to any signs that I'm getting stressed out or overtired. Doing Pilates under Gretchen's guidance and getting on the correct medications has dramatically reduced the number of flare-ups I experience.

Now I take three Pilates classes a week—one private and two classes—and I can keep up! Pilates always helps me feel like I'm normal again. It's a new normal, yes, but it's a blessing too. My body always feels better after class. I breathe better. I'm better at my job—all

thanks to Pilates. It's wonderful to finally feel well enough to have some fun and travel again. This year I went to Mexico and Paris!

THE UPSIDE OF ILLNESS

I never thought I would say this, but getting so sick brought me to life. What I have been through has changed me profoundly. I have been rediscovering who I am. I've become more compassionate, more giving, more loving, more centered.

Who knows where my journey goes from here? I still have nerve pain that comes and goes. I don't have feeling in my hands and my feet—I can feel pressure, but you could light my finger on fire and I wouldn't know it. But I know that I'm giving myself the best chance for whatever the next step is by doing Pilates. I know that putting myself back together after being hit by this awful illness would not have happened without Pilates. It has given me purpose and happiness again. As Joseph Pilates would say, I have "returned to life." **PS**

PARIS PHOTO BY THE PARIS PHOTOGRAPHER; OTHER PHOTOS BY JAMES WOODLEY PHOTOGRAPHY

