MY ILLNESS, MYSELF

The demands of modern life already feel overwhelming enough. But what if, on top of everything else, you had a health condition—one that required careful maintenance every single day? Meet six women who, while facing daunting physical challenges, embody grit and grace.

ILLUSTRATIONS BY DAN BEJAR

200,000 people in the U.S. live with narcolepsy.

THE PRO GOLFER
WHO'S GOT A GRIP ON HER FATIGUE

MY SLEEP PROBLEMS started in college. I was always drifting off in class, but I thought that was normal—everybody complained about being tired. Sometimes, though, the line between being asleep and awake got blurry. I'd find scribbled nonsense in my notes and had terrifyingly realistic dreams.

The constant drowsiness made driving scary. At first I thought something might be wrong with the exhaust in my old car, so I bought a new one. To stay awake, I drank coffee and even tried smoking cigarettes. I went vegan. I saw a homeopath who put me on vitamins and spirulina. He also sent me to a hormone doctor, who couldn't find anything wrong. Eventually, after I turned pro with the LPGA, I had an accident: While driving on a two-lane road, I dozed off behind the wheel, and my side mirror hit the mirror of another car. I was so lucky that was the extent of it, but it was a real eye-opener, so to speak.

NICOLE JERAY, 49
NARCOLEPSY

When I'd go out to dinner with my sponsors, I'd nod off at the table. It's not like I'd snore, but they'd ask questions and I'd answer without having a clue what I was saying. They later told me my eyes would glaze over. I even zoned out at my golf pro's funeral. It's like I'm suddenly not there.

The thing that finally led to my diagnosis was regular occurrences of something called cataplexy, in which intense emotional responses—laughter, anger, stress—make your muscles go limp. It happened when I dated a guy who made me laugh so hard I almost collapsed. It happened during a tournament in Minnesota when I hit a great shot, lost control of my limbs, and fell on the fairway. I went to an on-site doctor who called me the next day and asked, "Do you fall asleep a lot?" I said, "All the time." He rattled off some common narcolepsy symptoms: cataplexy, sleep paralysis, and hypnopompic hallucinations, which is the name for waking nightmares. Later a neurologist confirmed that I have type 1 narcolepsy. I was so excited to hear I wasn't dying that as soon as I walked out of the office, I had a cataplexy attack and sank, paralyzed, to the floor.

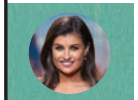
Some people use amphetamines to manage narcolepsy, but they just made me mean. Now I take an antidepressant that suppresses REM sleep so I can get more deep, restorative rest, and the drug Xyrem, which helps alleviate some of the daytime sleepiness and muscle weakness to prevent cataplexy. I make sure to hydrate and avoid carbs during the day: no waffles, or I'll be nodding off 30 minutes later.

I'm teaching golf at a high school and a golf course now. I love it, but I have to write down every name and lesson, because, as is true for many narcoleptics, my memory is shot. In the afternoon, I go out to my car for a 20-minute nap. Fortunately, the people I work for at the course understand.

Having narcolepsy has helped keep me in the game. Every year I've learned a little more about how to take care of myself and have felt a bit more alert, which has given me another burst of energy to keep pursuing my dreams. I still have to tamp down my excitement when I laugh or hit a good shot, but that reminds me to not get caught up in the outcome. Though if I see an alligator or a goose on the course that could cause trouble, I have to walk far away to avoid getting worked up! Also, in 2009, I started my campaign Swinging for Sleep—for every birdie I make in tournaments, I ask people to donate money to the Narcolepsy Network, and that makes me feel like I'm not just doing this for me. It really does give me something to keep playing for. **—AS TOLD TO AMY MACLIN**

NEED TO KNOW: NARCOLEPSY
This neurological disorder affects the brain's ability to regulate sleep-wake cycles. The onset of narcolepsy often occurs in adolescence. On average it can take ten years and visits to six different specialists to get an official diagnosis; narcolepsy is often confused with other sleep disorders, depression, psychiatric conditions, ADHD, and epilepsy. Approximately 60 percent of people with narcolepsy will experience cataplexy, the sudden loss of muscle control brought on by strong emotions. Treatment usually involves medication (to keep people awake, to help with cataplexy, and to induce and sustain nighttime sleep) and sleep hygiene strategies (the same ones the rest of us are supposed to follow, but they're especially important for people with narcolepsy). The condition lasts a lifetime but doesn't necessarily worsen with age—in fact, symptoms may even improve. For more info, go to wakeupnarcolepsy.org.

THE NEWS ANCHOR
WHOSE TICS GET NO AIRTIME



NIKKI BURDINE, 36
TOURETTE SYNDROME

WHEN I TELL PEOPLE about my condition, most of them say, "But you don't scream curse words!" It's true: My tics are mostly tapping, blinking, grunting, and, every now and then, screaming.

I was diagnosed when I was 12, around the time my dad, who's a Marine, was called up to serve in Operation Desert Storm. Often tics are brought on by stress, and doctors believe that could be what happened to me. I was doing a lot of counting and repeating; for example, I'd switch the light on and off a certain number of times. When I started yelping for no reason, my parents took me for an evaluation. That's how we found out it was Tourette.

High school was a struggle. I'd scream uncontrollably and then feel so embarrassed that I'd leave class. But I had great friends. I just found a photo of us all making a face that was one of my tics: I'd do selfie-style duck lips with my jaw clenched. We turned it into our thing!

Big life changes can be challenging for people with Tourette. My freshman year of high school, I went through a period when my tic was to lie on the ground, look up at a corner of the ceiling, and make this high-pitched scream. Going away to college was worse: My tics got so bad that I fell into a deep depression. My mom brought me to a doctor who put me on a bunch of antidepressants, and then more meds to counteract the side effects, until I was taking 19 pills twice a day. Managing that became its own issue.

It's a testament to my very supportive parents that I never thought Tourette should keep me from doing what I wanted to do, like becoming a news anchor at WKRN in Nashville. I studied journalism and political science in college and worked at the school TV station. I thought, *I'm really good at this, so I'm going to do it.* Also, when you're doing something you're passionate about, the tics tend to hold off.

There are times, though, when I have to deal with my tics on-air. I'll be reading a story about something tragic, like a car crash, and start worrying about the same thing happening to my loved ones. That anxiety gives me the urge to let it out: to stop reading the news, look up at the ceiling, and grunt. But I have to keep doing my job. As soon as my coanchor takes over, I let myself do something less obvious, like tap my fingers, and the anxiety will pass momentarily. It's exhausting.

I have other tricks I've learned through years of behavioral therapy. If I catch myself grunting, for instance, I can play it off like I'm clearing my throat. And over time, it's become easier to manage the condition. Last May, I became a mom, and during the last weeks before my maternity leave, I went through all kinds of ultrasounds and genetic testing. My anxiety was at an all-time high, and I caught myself on camera blinking incessantly. I didn't even realize it until I looked down at the monitor and thought, *Oh my God, I'm doing it on the air.*

I often see people blinking or tapping in a way that I recognize as obsessive behavior. Maybe they've never been diagnosed and never will be, because their condition isn't debilitating. In my case, I'm no longer embarrassed about having Tourette. I just don't want it to be a distraction from my job or a reason for people to treat me differently. The truth is, everyone is battling something. My struggle is just a little more obvious. **—AS TOLD TO A.M.**

An estimated 1 of every 162 children has TS.

NEED TO KNOW: TOURETTE SYNDROME (TS)
Involuntary, repetitive tics are the hallmarks of Tourette syndrome–both physical movements and sounds. The stereotypical tic of compulsive swearing affects only about 10 to 15 percent of people with TS. Tics typically emerge during childhood and level off in early adulthood. For some, tics may get worse during times of stress, anxiety, excitement, fatigue, or illness. Very often, TS correlates to other neurobehavioral and psychiatric disorders, such as ADHD, OCD, intrusive thoughts, learning disabilities, anxiety, and depression. When tics become overwhelmingly disruptive, behavioral therapy or medication (to suppress tics or address co-occurring neurological disorders) may be recommended. For more info, go to tourette.org.

THE MURALIST WHO PAINTS THROUGH PAIN

LIKE A LOT of people with multiple sclerosis (MS), I wake up tired. And then after eight or nine hours I'm ready to sleep again. So I try to cram a lot into each day.

In June 2012, I started losing feeling in my limbs, and I had pain radiating down my arm. Then half my tongue went numb, and fearing I'd had a stroke, I went to the hospital. Hours of tests revealed scars on my brain and spine, and the doctors diagnosed me with MS. By this point, life had already thrown a lot at me: I'd overcome a pretty aggressive form of cervical cancer, which was treated with a hysterectomy and radiation; I'd raised two kids by myself, one of whom is severely autistic and requires full-time care. So I thought, *I can get through this. I just need to find the right medicine.*

LYDIA EMILY ARCHIBALD, 48
MULTIPLE SCLEROSIS

My MS is the progressive kind—my health is gradually declining over time. I often feel as if fire ants are crawling between my gums and teeth and I'm getting needle injections all over my body. I have spasms, too. You know how it feels when you get a foot cramp? My MS causes that in random places, like in my face or behind my kneecaps. I take gabapentin and anti-inflammatories for the pain, and a muscle relaxer (methocarbamol) for the spasms. They help but also make me feel even more fatigued. My right foot drags when I walk, so I sometimes need to use two canes to get around. Because of my blurred vision, I'm legally blind in my left eye. It's all happening just like the pamphlets said it would.

I'm still working full-time, though. I'm an artist. My work has appeared in the Museum of Latin American Art and the Rosa Parks Museum, as well as in galleries in Milan, Berlin, and a few other cities. When my symptoms started, I was mostly doing activist street art. In my studio, I now do realistic oil portraiture for collectors. But I also continue to do murals all over the world—huge ones, like three or four stories high, to raise awareness of people who are living with chronic conditions.

To do large-scale work, I have a crew of two to four people. They're seriously fantastic. My 18-year-old daughter often paints with me when she's not in school studying to be a pilot. My manager is on location with me, and he helps with some of the detail work. Tremors in my hands have made it so I can't hold on to a paintbrush, but I strap my brushes to my hands with my kids' sparkly headbands and shoelaces. I outline the scene myself no matter how high it is, and I do hands and faces and other fine-tuning. I sit a lot and take regular breaks. For anything higher than 20 feet, I'll rent a mechanical lift—I can sit or even lie down in that while painting. For each mural I'm commissioned to paint, I do one for free in a neighborhood that needs it. I did one last summer in downtown L.A. It was a very colorful Art Nouveau–style mural that had two women—one black, one white—with two peacocks between them holding a banner that read THERE IS ALWAYS HOPE. END MS FOREVER.

Some days are better than others. Yesterday I barely made it to the couch. But I had an amazing cup of coffee! And my daughters sat with me and kept me company while they drew on their iPads. I didn't make art, but that's okay—I told myself I'd paint another day. When you're dealing with a chronic condition like MS, you have to adjust your expectations or you'll feel constantly defeated. **—AS TOLD TO CORRIE PIKUL**

1 million people in the U.S. have MS.

Women are up to three times more likely than men to develop MS.

NEED TO KNOW: MULTIPLE SCLEROSIS (MS)

In multiple sclerosis, the immune system attacks healthy tissue and cells within the central nervous system. This damages the myelin sheath covering nerve fibers and can cause degeneration of the nerves themselves, interrupting the flow of information between brain and body. Depending on where the damage occurs, MS can impair movement, coordination, sensation, and thinking. One way to help diagnose MS is to use MRI to identify "scars" (*sclerosis* is a medical term that refers to hardened tissue) in the brain, spinal cord, and optic nerves.

MS begins in one of two ways: relapsing-remitting (experienced by 85 percent of those with MS), which is characterized by attacks of new symptoms followed by recovery, or primary progressive (experienced by about 15 percent of those with MS), characterized by worsening of neurological function over time without remissions.

The condition is very rarely fatal; however, people with MS may live an average of about seven years less than the general population, in part because of complications from the disease. Studies show that starting treatment early can help slow the progression. For more info, go to nationalmssociety.org.

THE MODEL
WHO DOESN'T LET STIFFNESS STOP HER

VIKA ZUBAN, 32
RHEUMATOID ARTHRITIS

I WAS 13 YEARS OLD and living in Moscow when my alarm went off one day at 7:30 a.m. and I couldn't move—couldn't even open my mouth to call for my mother. I somehow managed to slide down my bed and tried to crawl toward the door. The pain was excruciating; then I fainted.

After three weeks in the hospital, doctors determined I had the autoimmune disorder rheumatoid arthritis (RA). I couldn't understand how it was possible: That was a disease for old people.

A rheumatologist put me on methotrexate, a medication that's used to treat certain types of cancer and, in low doses, can also help alleviate arthritis pain. The medication lessened the pain in my joints enough that I could do the activities I loved: gymnastics, dancing, horseback riding. But my side effects—dizziness, nausea, weight loss, blurred vision, depression—were pretty intense, so at 18, I went off it. After a year, the pain came back, particularly in my hands and fingers. My wrists were so stiff, I couldn't bend them; they were like tree branches.

I'd started modeling at age 13—my older sister was discovered walking through Red Square, and after I expressed interest, she connected me with her agent. When I turned 20, after I'd been off the medication for a while, the swelling worsened noticeably. At a beauty shoot, the stylist tried to put rings on my fingers and they didn't fit. I played it off like, "Oh, you should've asked my agency for my correct ring size." As a model, you're expected to be perfect from head to toe. So I would practice in front of the mirror to figure out angles and hand positions where you couldn't tell anything was different about me.

When I wasn't on a modeling job, in public I kept my hands balled up into fists because I was afraid people would notice them. I told myself I was exercising my hands. But in Miami, I met a massage therapist who showed me how to stretch my hands by opening up my fingers—and it made such a difference. Now I do this all day long. I also follow the Clean Program, a health-focused system of eating that's gluten- and dairy-free and involves lots of probiotics, supplements, and fish high in omega-3s. And I avoid acidic foods, which make my arthritis worse.

I've found that the more openly I talk about this disorder, the easier it is to cope. Seven years ago, I got signed by an agency in Milan, but when it came time for them to take photos of my hands to have on file, I started sweating. I decided to just come out with it: "I have arthritis in my joints, and my hands aren't perfect." The agent and booker were so supportive! They thanked me for telling them and said that if I needed to explain that to a client for a job, they'd have my back. I booked three castings that week.

Since then, I've been much more open about having RA. On one recent shoot, a male model and I were supposed to put our hands together to make the shape of a heart, but my stiff fingers wouldn't cooperate. The photographer was someone I'd worked with before, and she knew about my condition. She came over and gently placed my fingers in the correct position. Then she went back and captured the shot.

My rheumatologist in London said that what's happening now is just the beginning. The pain could eventually spread to the rest of my body. Even in 2008, my X-ray showed a bit of inflammation in my left knee and ankle as well as my hands. I try to stay positive and focus on taking care of myself. I've done a pretty good job so far. **—AS TOLD TO MOLLY SIMMS**

NEED TO KNOW: RHEUMATOID ARTHRITIS (RA)
In this disease, the immune system attacks the body's tissues. The resulting inflammation can cause joint swelling, pain, and stiffness. RA commonly affects hands and toes first, then often progresses to wrists, elbows, knees, ankles, hips, and shoulders (usually on both sides of the body, so if one wrist is affected, the other is, too). Symptoms may also include a loss of energy or appetite, low fevers, and lumps beneath the skin in places like the hands and elbows. Flare-ups can last days or months. Over time, inflammation can lead to bone damage and loss of cartilage, which may cause joint deformity. In addition to meds to reduce inflammation and pain (including NSAIDs like ibuprofen, as well as corticosteroids), a growing number of disease-modifying antirheumatic drugs work to alter the course of RA. For more info, go to arthritis.org.

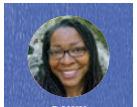
1.3 million people in the U.S. have RA.

70% of RA patients are women.

3 million people in North America have UC.

NEED TO KNOW: ULCERATIVE COLITIS (UC)
One of the most common types of inflammatory bowel disease, ulcerative colitis is characterized by chronic inflammation of the large intestine—specifically, the inner lining of the rectum and colon. The inflammation causes tiny ulcers to develop and produce pus and mucus, which results in abdominal pain and a reoccurring urge to have a bowel movement; symptoms can also include diarrhea and blood in the stool. There may be gaps of months or years between flare-ups, but because there isn't yet a cure, symptoms will eventually return. Treatment usually includes dietary restrictions, prescription meds to maintain remission and manage flare-ups, and, in some cases, surgery to remove the colon and rectum. For more info, go to crohnscolitisfoundation.org.

THE ASSISTANT DIRECTOR
WHO FIGHTS THE URGE



DAWN BRIDGEWATER, 45
ULCERATIVE COLITIS

AS A FIRST assistant director of TV commercials, promos, and teasers, I manage the set. My job is to tell the entire crew what to do and to be in control at all times. The irony is, I often can't even control my own bowels.

I was diagnosed with ulcerative colitis 18 years ago, at age 27. I had been feeling pretty run-down for a while, and then I noticed blood in my stool. I'd always had digestive issues, but this scared me, so I went to the ER, and then to a gastroenterologist. He looked at me and said, "You're not the typical colitis patient. I usually treat older Jewish men." I still haven't met any other African Americans who have this. The doctor prescribed a drug called mesalamine and advised me to avoid stress. I was like, okay, sure, I'm a broke production assistant in my 20s living in New York City—no stress here.

My condition is considered "mild to moderate," and yet at least every two years—often less—I have flare-ups that last from six weeks to three months. The worst involve going to the bathroom up to 20 times a day. I'm bloated and irritated, and expelling blood and mucus. It's foul smelling. It's traumatic.

For every job I'm offered, I assess the situation: How many bathrooms are on set? Because if there's just one for the talent and the crew, I'll pass. How far are the bathrooms from the soundstage—could I make it in an emergency? Who else is working—are they familiar with me and my bathroom habits? I'm not shy about discussing it; besides, I have to communicate with people on the set with my walkie-talkie even when I'm on the toilet. I might be trapped in there for ten or 15 minutes at a time.

Before a job, I do meal prep like crazy. Sometimes the caterer brings food I can eat, like avocados, broth, white rice. But most of the time, I pack my own meals and snacks and eat them in the car so I'm not tempted to nibble on things that will aggravate my condition.

At my 42nd birthday party, some friends started sharing embarrassing stories, and I was like, "Guys, I've got this." Here's one for you: I'd developed a bacterial infection right before an important shoot. I wore Depends as a backup and constantly trotted back and forth to a restroom in an office building. On one of my trips, just as we were finishing for the day, I didn't make it to the stall in time. My pants, underwear, and socks were ruined, and I had to throw them away. I was frantically trying to clean up before anyone walked in, but I had nothing to change into. Then I had an idea: I happened to be wearing a hoodie bearing the name of my production company. I took it off, zipped it up, and stepped into it like a skirt. I called an assistant and asked her to bring me my bag. Then I casually walked out of there like nothing was wrong, with poop in my shoes and AWESOME DAWN scrawled across my butt, and drove myself home. Sometimes I just have to laugh about it. **—AS TOLD TO C.P.**

THE COLLEGE STUDENT WHO PUTS HERSELF BACK TOGETHER

ELAINE KATZ, 25
EHLERS-DANLOS SYNDROME

IF YOU SAW ME walking across campus, you might think I was an athlete. My knees are framed by strips of kinesiology tape, and I'm always wearing spandex leggings and compression shirts. But my body can barely function normally: My hips dislocate if I sit on hard surfaces, and if I accidentally cross my legs, my kneecaps might pop out of place. The clothing I wear literally holds my joints in position.

I have a form of Ehlers-Danlos syndrome (EDS), meaning that in my body, the collagen that fortifies connective tissues—think of it as the body's glue—doesn't function correctly. I have hyperflexible, unstable joints, and my childhood and early teen years were riddled with broken bones, including a recurrent spinal fracture. When I was 10, on a family vacation in Rome, walking on uneven concrete caused me to fracture my back. In April of my freshman year at Harvard, I woke up one day with two dislocated hips and a dislocated shoulder just from rolling over in my sleep. That's when I took a year off from school, during which my mom and I visited an amazing geneticist. She did blood work and a clinical exam called a Beighton score, which analyzes things like how far you can bend your thumbs and whether your knees kink out in a way they shouldn't. I had eight out of nine signs of EDS. At age 21, I finally understood what was going on with my body.

There aren't any medications specifically for EDS, but each morning, I spend 15 minutes swallowing at least 50 types of supplements, including some derived from organ meats and collagen-rich tissue from cows. Eating a low-carb, high-fat ketogenic diet has radically improved my G.I. function and energy, and though it hasn't helped stabilize my joints, I notice less bruising and swelling. My jaw dislocates if I chew solid foods, so I live on bone broth and smoothies made with almond milk, avocados, and collagen protein.

Movement is hugely important for me because when my muscles aren't firing, my joints are more prone to give way. Once a week, I go to a structural-alignment specialist who examines my posture and gait and adjusts my limbs and spine. I do physical therapy three times a week, and I'm a fan of less traditional practices like cryotherapy and infrared saunas, which help reduce my inflammation and pain.

If I didn't know how to pop my joints back on my own, I would spend my life in the ER. I've become a whiz at banging my arms into their sockets against the sides of buildings and doing lunges to get my hip in place. I don't have a lot of time to see friends at night because I'm often relocating my joints and lying down covered in ice packs. Socializing is challenging anyway because of the restrictions on what I can eat and where I can sit. In so many ways, I'm not the average college student: I've never kissed a boy, been on a date, or taken a drink or a recreational drug of any kind. I consider myself lucky to have my amazing, supportive best friend, Olivia. We go for walks together—we're always wandering around the nature preserves of Cambridge, laughing and chatting.

Last spring I experienced what felt like a headache on steroids—I had to prop my chin on my hands just to keep my head up. That summer I was selected for a research internship through the Harvard Stem Cell Institute. Yet my doctor cautioned me against performing lab work, which requires peering over cell cultures and microscope lenses in a position that could worsen my neck pain. So my lab mentor assigned me a computer-based project and gathered ergonomic furniture from campus buildings so I could still be part of the lab atmosphere. The work I did during that internship has potential therapeutic ramifications for people with Duchenne muscular dystrophy, as well as aging in general. It was incredibly fulfilling.

By September, I was still wearing a neck brace, felt exhausted no matter how much I slept, and couldn't think clearly. My parents pulled me out of school and brought me home to New York City, and my mother, a doctor, asked experts to investigate whether I might be leaking cerebral spinal fluid. That turned out to be the culprit. The leak was patched over, but that led to further complications, so I took the rest of the semester off.

This isn't the life I would've chosen for myself, but I've grown in so many ways. I dislocate at least two body parts a day, so I've learned to expect the unexpected. I'm writing a memoir so I can share my story. And having to deal with my health has inspired me to investigate the biological underpinnings of disease. My challenges have given me a sense of pride in who I am, EDS and all.

—AS TOLD TO M.S.

At least 1 in 5,000 people worldwide has EDS.

NEED TO KNOW: EHLERS-DANLOS SYNDROME (EDS)
Few people had heard of this rare syndrome—actually a group of related yet varied connective-tissue disorders—until last year, when British actor Jameela Jamil, pop singer Sia, and actor-director-writer Lena Dunham all revealed that they have Ehlers-Danlos syndrome. Common symptoms include hypermobile joints, skin that bruises easily, and chronic musculoskeletal pain. Treatment often focuses on preventing serious complications through physical therapy and assistive devices like braces, and on pain management to increase comfort. Most types of EDS are not known to have any negative effect on life expectancy. For more info, go to edswellness.org.