

'You Don't Look Anorexic'

New research shows that our assumptions about eating disorders are often wrong — and that many larger-bodied people are starving themselves.

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Sharon Maxwell is recovering from atypical anorexia. She suffered from disordered eating for 19 years before receiving a diagnosis. Ryan Pfluger for The New York Times

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Sharon Maxwell spent much of her life trying to make herself small. Her family put her on her first diet when she was 10. Early on Saturday mornings, she and her mother would drive through the empty suburban streets of Hammond, Ind., to attend Weight Watchers meetings. Maxwell did her best at that age to track her meals and log her points, but the scale wasn't going down fast enough. So she decided to barely eat anything on Fridays and take laxatives that she found in the medicine cabinet.

Food had long been a fraught subject in the Maxwell household. Her parents were also bigger-bodied and dieted frequently. They belonged to a fundamentalist Baptist megachurch where gluttony was seen as a sin. To eat at home was to navigate a labyrinth of rules and restrictions. Maxwell watched one time as her mother lost 74 pounds in six months by consuming little more than carrot juice (her skin temporarily turned orange). Sometimes her father, seized with a new diet idea, abruptly ransacked shelves in

the kitchen, sweeping newly forbidden foods into the trash. Maxwell was constantly worried about eating too much. She started to eat alone and in secret. She took to chewing morsels and spitting them out. She hid food behind books, in her pockets, under mattresses and between clothes folded neatly in drawers.

Through Maxwell's teenage years and early 20s, eating became even more stressful. Her thoughts constantly orbited around food: what she was eating or not eating, the calories she was burning or not burning, the size of her body and, especially, what people thought of it. Her appearance was often a topic of public interest. When she went grocery shopping for her family, other customers commented on the items in her cart. "Honey, are you sure you want to eat that?" one person said. Other shoppers offered unsolicited advice about diets. Strangers congratulated her when her cart was filled with vegetables.

As she grew older, people at the gym clapped and cheered for her while she worked out. "People would say: 'Go! You can lose the weight!'" she says. While eating in public, other diners offered feedback — and still do to this day — on her choices, a few even asking if she wanted to join their gym. Some would call her names: Pig, Fatty. Sometimes people told her she was brave for wearing shorts, while others said she should cover up. She was always aware, whether she

wanted to be or not, of how others viewed her body.

Maxwell tried just about every diet she could find: juice cleanses, Atkins, SlimFast, South Beach, Mediterranean, Whole30 and Ezekiel, a regimen based on biblical references. She tried being vegetarian and vegan and paleo. She tried consuming less than 500 calories a day and taking HCG, a fertility hormone rumored to suppress appetite but flagged by the F.D.A. as risky and unproven for weight loss. During periods of religious fasting at her church, she would take the practice to an extreme, consuming nothing but water for days (and on one occasion, two weeks). "I passed out a few times, but I did it," she says. Sometimes she exercised more than three hours a day in high-intensity interval-training sessions and kickboxing classes. Eventually, she started vomiting up her food.

Every day, Maxwell stepped on the scale and internalized the number as a reflection of her self-worth. Often, the number on the scale went down. But if she let up on her rigid food rules even briefly, the number shot back up like a coiled spring. "I just cycled through that," she says, "but it became harder and harder each time to get the weight off."

During the many years of dieting and deprivation, Maxwell experienced mysterious health problems. For a decade, starting when she was 16, she almost never had her period. She was always cold. She often had dizzy spells and

occasionally passed out in class. When she was in college, she fainted three times in one day and was taken to the emergency room. For an appointment with an endocrinologist one year, Maxwell took a purse full of small plastic bags. Each one contained a day's worth of hair, clumps that accumulated in her brush or had fallen in the shower drain. Her head was pocked with bald spots. The doctor was pleased with her weight loss and, to her memory, didn't seem too concerned about her other symptoms. "Anything that made the scale go down," Maxwell says, "I was given a pat on the back."

Four years ago, at the age of 25, Maxwell walked into her primary-care doctor's office near Scottsdale, Ariz., where she lived and worked as a middle school teacher. She was there for an annual physical, and she was prepared to be told to lose weight, as she had almost always been instructed. But this time, the doctor, an osteopath, started asking unusual questions. Maxwell's blood work showed abnormally low iron and electrolyte levels. The doctor asked Maxwell what she was eating and what she was doing in relationship to food. Was she starving herself? Was she vomiting on purpose? Maxwell was surprised by this line of questioning. "These are things I had hidden my whole life from my family, my friends, doctors," she says.

The osteopath told her she thought Maxwell had an eating

disorder and suggested arranging treatment right away. Maxwell would later be diagnosed with atypical anorexia nervosa, an increasingly common yet little known eating disorder that shares all the same symptoms as anorexia nervosa, except for extreme thinness. Just as many people, and possibly many more, suffer from atypical anorexia.

At the physical, Maxwell stared at her doctor in disbelief. She always thought that eating disorders were for skinny people. "I laughed," she says. "I don't use language like this any longer, but I told her she was crazy. I told her, 'No, I have a self-control problem.'"

For centuries, the eating disorder that would become known as anorexia nervosa mystified the medical community, which struggled to understand, or even define, an illness that caused people to deliberately deprive themselves of food. As cases rose over the course of the 19th and 20th centuries, anorexia was considered a purely psychological disorder akin to hysteria. Sir William Withey Gull, an English physician who coined the term "anorexia nervosa" in the late 1800s, [called it a perversion of the ego](#). In 1919, after an autopsy revealed an atrophied pituitary gland, anorexia was thought to be an endocrinological disease. That theory was later debunked, and in the mid-20th century, psychoanalytic explanations arose, pointing to sexual and developmental dysfunction and, later, unhealthy

family dynamics. More recently, the medical field has come to believe that anorexia can be the product of a constellation of psychological, social, genetic, neurological and biological factors.

Since anorexia nervosa became the first eating-related disorder listed in the Diagnostic and Statistical Manual of Mental Disorders in 1952, its criteria have shifted as well. Initially, anorexia had no weight criteria and was classified as a psychophysiological disorder. In a 1972 paper, a team led by the prominent psychiatrist John Feighner suggested using a weight loss of at least 25 percent as a standard for research purposes, and in 1980, the D.S.M. introduced that figure in its definition (along with a criterion that patients weigh well below "normal" for their age and height, although normal was not defined). Doctors who relied on that number soon found that patients who had lost at least 25 percent of their body weight were already severely sick, so in 1987, the diagnosis was revised to include those who weighed less than 85 percent of their "normal" body weight (what qualified as normal was left to physicians to decide). In the 2013 D.S.M., the criteria shifted again, characterizing those who suffer from anorexia as having a "significantly low weight," a description that would also appear in the 2022 edition.

In that 2013 edition, a new diagnosis appeared — atypical

anorexia nervosa — after health care providers noticed more patients showing up for treatment with all the symptoms of anorexia nervosa except one: a significantly low weight. Those with atypical anorexia, doctors observed, suffer [the same mental and physical symptoms as people with anorexia nervosa](#), even life-threatening heart issues and electrolyte imbalances. They restrict calories intensively; obsess about food, eating and body image; and view their weight as inextricably linked to their value. They often skip meals, eat in secret, adhere to intricate rules about what foods they allow themselves to consume and create unusual habits like chewing and spitting out food. Others exercise to the point of exhaustion, abuse laxatives or purge their meals. But unlike those diagnosed with anorexia, people with atypical anorexia can lose significant amounts of weight but still have a medium or large body size. Others, because of their body's metabolism, hardly lose any weight at all. To the outside world, they appear "overweight."

Starting in the mid-2000s, the number of people seeking treatment for the disorder rose sharply. Whether more people are developing atypical anorexia or seeking treatment — or more doctors are recognizing it — is unknown, but this group now comprises up to half of all patients hospitalized in eating-disorder programs. Studies suggest that the same number of people, even as many as three times as many, will develop atypical anorexia as traditional anorexia in their

lifetimes. One high estimate suggests that as much as 4.9 percent of the female population will have the disorder. For boys, the number is lower — [one estimate was 1.2 percent](#). For men, it is likely even lower, though little research exists. For nonbinary people, the number jumps to as high as 7.5 percent.

Across the board, the pandemic exacerbated eating disorders, including typical and atypical anorexia, through increased isolation, heightened anxiety and disrupted routines. Hospitals and outpatient clinics in the United States and abroad reported the number of consultations and admissions doubling and tripling during Covid lockdowns, and many providers are still overbooked. "Almost all of my colleagues, we're at capacity," says Shira Rosenbluth, an eating-disorder therapist who specializes in size- and gender-diverse clients. They are seeing clients who practice more extreme food restriction and experience more intense distress around body image and eating habits. "The demand has increased, the level of severity has increased," Rosenbluth says. "We've never seen waiting lists like this for treatment centers."

Shira Rosenbluth, an eating-disorder therapist specializing in size- and gender-diverse clients, at home in West Hollywood, Calif. Ryan Pfluger for The New York Times

Despite its prevalence, atypical anorexia is still considered

widely underdiagnosed and under-researched, and many primary-care doctors have never heard of it. "Some people being at a standard body weight or overweight can be perplexing to the untrained eye," says Karlee McGlone, senior manager of admissions and outreach for U.C. San Diego Health Eating Disorders Center. "It is still a surprise for nonspecialized clinicians."

Patients, too, are in the dark about atypical anorexia. "Most people in higher-weight bodies are shocked to hear that they have anorexia," says Rachel Millner, a psychologist based in Pennsylvania who specializes in eating disorders among people with larger bodies. "Nobody ever told them that you can be in a higher-weight body and have anorexia, and they're convinced that their problem is their weight."

In 2020, Erin Harrop, an assistant professor of social work at the University of Denver, completed a survey of 39 people with atypical anorexia, most of whom were obese, and found that participants endured the disorder for an average of 11.6 years before seeking help. They lost an average of 64 pounds, and a quarter of the group had yet to receive treatment. (By comparison, [the treatment delays for anorexia](#) are, on average, 2.5 years; for bulimia, 4.4 years; and for binge-eating disorder, 5.6 years, according to a 2021 review.)

To make it easier for people with atypical anorexia to be

screened, treated and insured, there's a growing movement in the field to collapse the categories of anorexia and atypical anorexia into one — to no longer see them as separate illnesses, to decouple anorexia from its virtually synonymous association with thinness. "For years, we have thought about anorexia nervosa in one way," says Carolyn Costin, an eating-disorder therapist who founded an eating-disorder treatment center and is a co-author of "8 Keys to Recovery From an Eating Disorder." "But the way people think about it and how they want to define it is changing. It would be a paradigm shift within the field."

Many, however, are fiercely resistant to letting go of the metric of weight. It would require altering the organizing principle by which the public and the greater medical field conceive of the condition. It would also require recognizing that anyone, in any body, can starve themselves into poor health — and you'd never know it by looking at them.

It took Maxwell a long time to process that she had an eating disorder. She had been so steeped in the gospel of dieting that it was hard to accept that restricting her food was not unequivocally healthy. But as her doctor instructed, she began making visits to the hospital for intravenous fluids and started taking iron supplements. At night, she began attending outpatient sessions at Liberation Center, a now-shuttered facility in Phoenix, where she ate dinner with other

clients and attended group therapy. The staff at Liberation told her she needed more intensive treatment and recommended attending a residential program.

In the summer of 2018, after teaching through the rest of the school year, Maxwell agreed to go to a center in Monterey, Calif., that was covered by her insurance. A day after she arrived, however, her insurance rescinded approval: Because of her weight, the company didn't believe she was sick enough to meet the criteria for residential care for eating disorders. She was at once ashamed and incensed. Her aunt drove five hours to pick her up, and she spent much of the next 10 days on the phone with the insurance company.

Her insurance eventually authorized her to go to another facility, the Center for Discovery Rancho Palos Verdes, which sits on the Southern California coast. Maxwell's three-month stay would consist of group meals, outings to restaurants to practice dining in public settings, yoga and therapy. "I went with the expectation that as soon as I walked in the door, they would be the people who would help me finally become thin once and for all," she says. Instead, on her first day, a dietitian at the center explained that she would need to eat three balanced meals and three snacks a day to recover. Her treatment plan also required that she abstain from almost all forms of exercise so her system could recalibrate. Maxwell panicked. She had never consistently eaten that much in her

entire adult life, and she still felt that her body was a problem to be fixed.

Maxwell already harbored a deep mistrust of the mental-health profession. When she was growing up, she remembers a pastor at her church preaching that psychiatry was the work of the devil. The message seemed to be that anxiety was sinful, a sign of faithlessness. Maxwell had left her church two years earlier, but its lessons were still lodged deeply in her mind. She couldn't abandon her long-held belief, one that her doctors reinforced for much of her life, that thinness was the primary measure of health.

Maxwell forced herself to go along with each step of the treatment program. She tried to eat three meals and three snacks a day, even though it caused her excruciating fear. For years, her thinking had revolved tightly around food and exercise; and during twice-weekly individual therapy sessions and daily group therapy, she tried to learn how to redirect these thoughts. She started to talk about the self-judgment, shame and childhood trauma that led to rigid behaviors and an overreliance on control, both central features of restrictive eating disorders.

About five or six weeks into treatment, it dawned on her just how much damage she had done to herself. Her esophagus burned from years of purging. She experienced heart palpitations and was often dizzy from orthostatic

hypotension (a type of low blood pressure that leads to dizziness and fainting), and her hair and nails were thin and brittle from malnutrition. "I started to realize, holy shit, this is real," she says. "I started to see what it had done to my body, the magnitude of it."

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Over the ensuing weeks, Maxwell began eating enough food that the staff allowed her to go on walks and swim, not to burn calories but as a part of learning how to live a balanced life. Her physical symptoms started to ease. Her vital signs and blood work improved. She felt less dizzy, her heartbeat more regular. She got her period back for the first time in a decade. And perhaps most surprising, she was not gaining weight despite eating more food.

To help her overcome her self-judgment, a nurse suggested that she look in the mirror and express what she liked about her body. At first, Maxwell couldn't think of what to say. She could hardly make eye contact with her own reflection. But eventually she thought of something. "I'm grateful for my curly hair," she said, looking at the nurse in the mirror.

When a human body is starved for long enough, it

undergoes a complex series of biological, metabolic and hormonal changes to ensure its own survival. Every system moves to conserve energy, and the body begins to mine muscle and fat for glucose to keep the heart running and the brain functioning. The metabolism slows, which is why some people can eat very little and hardly lose any weight.

Digestion simmers down, sometimes causing gastrointestinal trouble, and body temperature plummets while blood flow decreases. Many people who chronically undereat shiver with cold, their hands and feet feeling especially icy. If malnutrition worsens, their hair becomes fragile and falls out and muscle mass dwindles, including within the heart.

People with severe anorexia of any kind can have orthostatic hypotension, heart rates lower than 60 beats per minute and electrolyte imbalances that may cause arrhythmias or even lead to cardiac arrest. Eventually a malnourished body can shut down the production of sex hormones. From what little research on atypical anorexia exists, the medical complications appear to be the same as anorexia and occur in similar rates across body sizes, with the exceptions of bone density loss and low blood sugar, which are worse in those who are emaciated. Recent research has found that body size is a less relevant indicator of the severity of both eating disorders than other factors, including the percentage of body mass lost, the speed of that loss and the duration of

the malnourished state.

Among scientists, there is consensus that atypical anorexia and anorexia share the same medical and nutritional issues, but one of the big remaining questions is whether the psychopathology is the same (some clinicians believe that it is, but minimal research exists to confirm this). In the slim populations they have studied, psychologists have observed a grim momentum to the illness: Sufferers lose just a few pounds and then, all of the sudden, they compulsively want to lose more, as if a mental switch flips. Genetic predispositions may explain why some people lose weight and their minds tip into disordered eating while others do not. Immediate female family members of a patient with anorexia nervosa are 11 times as likely to develop it as females in the general population, according to one study.

In the short term, resisting hunger pangs can make people feel powerful and even euphoric. But soon the effects of starvation on the brain set in: mental fog, difficulty concentrating, memory issues. People become secretive, irritable and inflexible in their thinking. The gray matter of the brain shrinks, and it appears that the neural pathways related to rewards can be reversed. (It's not clear if that's a pre-existing trait or an effect of the illness.) Food that typically results in a dopamine hit now inspires dread. The crippling fear of weight gain begins to outcompete the biological urge

to eat, spiraling downward into more weight loss and distorted thinking.

In a famed [1944 study known as the Starvation Experiment](#), [Prof. Ancel Keys](#) of the University of Minnesota and his team observed the impact of food deprivation on people's relationship to eating. They persuaded 36 young, healthy men to undergo six months of semi-starvation and five months of resumed feeding to determine the best means for treating people who suffered famine and forced starvation in World War II. The men lost 25 percent of their body weight. And over the course of the study, these otherwise mentally fit young participants developed many of the symptoms of anorexia, bulimia and binge-eating disorder, including obsession with eating, cutting food into small pieces, bingeing and purging, excruciatingly slow eating and, even five months after they regained weight, body-image issues. More recent research suggests that [losing just 5 percent of one's body weight can be associated with a clinically significant eating disorder](#).

Because of the complex interplay between the physical and mental symptoms of starvation, the first steps to recovery for people with malnutrition are to eat more and to gain weight, a process called refeeding or renourishment, before working on the behavioral and cognitive aspects of the disease. But for people who are acutely ill, eating too much

too fast increases the risk of potentially fatal fluid and electrolyte imbalances that can develop in malnourished bodies. Specific protocols govern how people with anorexia are refeed, and research is still emerging on how to renourish people with atypical anorexia.

A 2019 study led by Andrea K. Garber, a professor of pediatrics and chief nutritionist for the Eating Disorder Program at U.C. San Francisco, found that when atypical anorexia patients were given the same high-calorie foods in the same portions as anorexia patients, they did not recover as well. "It might sound like a no-brainer," Garber says. "They have a larger body size, and so we believe they need more nutrition to recover."

But clinicians, many of whom have been trained to focus on weight as a predominant health measure, have to navigate how best to advise patients who face both the perils of a potentially fatal restrictive eating disorder and the health risks associated with larger body sizes. In one case study, for example, a 15-year-old girl with atypical anorexia had stopped having her period and was hospitalized for severe malnutrition and bradycardia, a dangerously slow heart rate. Refeeding helped her recover from her eating disorder, but then she lost her period again because of polycystic ovarian syndrome, a condition that occurs in people of all sizes but is more common and often more severe in people who have

higher percentages of body fat.

Some psychologists report that atypical anorexia is harder to treat than anorexia nervosa because the fear of weight gain is even greater in people who have been bullied and shamed for their size. The biggest difference in the two conditions, some psychologists believe, may be how they are perceived by the outside world, biases that persist even in places where patients go to seek help.

After she left the Center for Discovery Rancho Palos Verdes and moved to South Carolina, Maxwell started a partial hospitalization program at the Eating Recovery Center in Greenville. She immediately began noticing how her size was affecting the quality of her treatment. When she arrived, a staff member put her in a room and told her to wait, while the people with "normal" eating disorders gathered next door. Her words felt like a gut punch. At lunch, she was told to sit by herself at the back of the dining room, while the other clients sat together with their backs to her. "I was like, I can't sit with them?" she says. The center had mistaken her diagnosis for binge-eating disorder and had a policy of separating those clients from the others.

Sometimes staff members singled her out and had her eat less than small-bodied patients. At a group-therapy session in which she was the only large person in the room, another patient shared that she would rather die than be fat. "Her

literally expressing that while I'm in that room — that to be me, to live in this body that I have to recover in, would be worse than anything — it's just ostracizing," Maxwell says. (The Eating Recovery Center does not comment on individual patient experiences, but since 2021, it says, it has made efforts to counteract weight stigma in its treatment centers.)

Erin Harrop, the social-work professor, who uses they/them pronouns, has experienced both ends of the treatment spectrum for eating disorders. They attended treatment for anorexia in their early 20s with a small body; then, several years later, they returned for treatment for atypical anorexia. Harrop was shocked by the differences. Even though they had been diagnosed with atypical anorexia, had lost nearly 20 percent of their body weight and were experiencing orthostatic blood pressure, the therapist at the treatment center did not believe their diagnosis and even encouraged them to compare themselves to "sicker" residents — those with smaller bodies. Comments about their body from doctors, dietitians and other professionals exacerbated their disordered thinking. They were bullied by peers for their weight, and the kitchen staff limited their food intake: When their peers ate bagels, they received a bite-size one.

In their 2020 survey of people with atypical anorexia, Harrop discovered that every participant had also been overlooked, misdiagnosed or excluded. Almost everyone had approached medical providers with symptoms of malnutrition, like hair loss, dropped periods, fainting, vomiting blood or dry or bleeding skin. But it took years, and sometimes decades, for anyone to screen them for an eating disorder. As a teenager, one participant, Eli, believed she had an eating issue and approached her doctor about it. The physician disagreed, instead telling her that she "could actually probably lose a little bit of weight," she said. It took eight more years before Eli began treatment for atypical anorexia. Another participant, Lexi, remembered a physician telling her: "You don't look anorexic. You don't look underweight."

Tori, also a participant, was diagnosed by her therapist but was then denied treatment referrals by her physician, who said she was too overweight. Layla, who consumed nothing but bone broth and lost 22 percent of their body weight, was diagnosed with "compulsive eating." Two participants had been hospitalized for being suicidal and for their eating-disorder symptoms but were barred from joining an eating-disorder support group because, they were told, they were too large. One participant, while seeking treatment at a center for eating disorders, was given a diet book.

Shira Rosenbluth, the eating-disorder therapist, has struggled with atypical anorexia and says treatment actually made her sicker. At one center, a nurse insisted that she had a food addiction and continually commented on her meals, which were dictated by the dietitian. The nurse recommended Overeaters Anonymous and the controversial GreySheet diet, a low-carb, no-sugar, no-alcohol 1,200-calorie-per-day regimen for people who compulsively overeat, even though Rosenbluth had lost significant weight. At various points, she experienced orthostatic blood pressure and abnormally low phosphorus, which can cause bone pain, irregular breathing, numbness or heart failure. Blood work showed that her pancreas wasn't functioning properly. Still, she was given less food than smaller-bodied patients. At another center, when patients had ice cream cones, she got a kid-size one.

For two years, she went from treatment center to treatment center, hoping that each one would be better than the last. Finally, she gave up altogether and stayed with a friend, a psychologist in the field, who oversaw her meals and helped her become more stable. "For the first time," she says, "I was getting care without a stigma attached."

In recognition of the inconsistent care that people with atypical anorexia sometimes receive, a small vanguard of professionals in the field are experimenting with ways to

improve treatment for people with larger bodies. Erin Harrop runs weight-stigma training sessions for treatment centers, hospitals and social-work graduate students. Lisa Brownstone, an assistant professor at the University of Denver, is piloting psychotherapy groups for eating-disorder patients who have been traumatized by weight stigma. Centers like Opal: Food and Body Wisdom in Seattle have hired body-diverse staff members, created physical spaces that accommodate a range of bodies and trained therapists on size inclusivity. But there's only so much they can do before butting up against systemic challenges, and the biggest one is discriminatory insurance coverage.

Some atypical anorexia patients are authorized for treatment for only two or three weeks before they are cut off — an almost impossibly short period of time to recover. Certain insurance companies outright deny coverage for people with larger bodies. Lexi Giblin, Opal's executive director, has seen some patients with atypical anorexia not receive authorization for treatment even though they have the same symptoms as someone with a smaller body. "The invalidation of the insurance company can certainly contribute to the symptoms themselves," Giblin says. "They can become part of the eating disorder. We've had folks who are denied authorization then come back later, and their eating disorder has escalated since the last time we saw them. That's pretty common."

The issue stems not only from a lack of knowledge about a relatively new diagnosis; it's also a product of how the diagnosis is named and coded. Because it is labeled "atypical" and filed under the murky "other specified feeding or eating disorder" category, it is often seen as less dangerous. "It's an absurd diagnosis," says Jennifer L. Gaudiani, an internist who specializes in eating disorders in Denver and the author of "Sick Enough: A Guide to the Medical Complications of Eating Disorders." "There's nothing atypical about it. If there's anything atypical, it's the people who get underweight."

To make it easier for people to secure care, some therapists, social workers and researchers have been advocating combining atypical anorexia and anorexia by removing the requirement to have a "significantly low weight" from the standard anorexia diagnosis. But the idea of merging the categories has ignited strong feelings within the field, with fierce support by people with larger bodies who have suffered from weight discrimination, and incredulous opposition (largely behind closed doors) among some researchers who have devoted their careers to the illness as it is currently described.

Opponents argue that such a change would be premature; much remains unknown about atypical anorexia, including its brain biology, genetics and psychopathology, all of which

could help inform treatment and the development of drugs. (To date, there are no pharmacological treatments for anorexia.) Distinguishing between the two, they say, is crucial to studying them effectively. "It is not helpful to us if we put the atypical anorexia nervosa folks in exactly the same bucket as the typical anorexia nervosa," says Guido Frank, a psychiatry professor at U.C. San Diego who specializes in the brain biology of eating disorders. "I'm not saying they're any less ill — that's the last thing I want to say. To define and devise the right treatments for each of the subgroups, we're best advised that we also study them in a way separately or along a trajectory."

But proponents of the change say that the weight requirement for anorexia causes those with medium and larger bodies to be excluded from many studies. They also point out that the line between the two diagnoses is not particularly scientific and has harmful effects on patients' ability to secure care. "From my personal patient experience," Harrop says, "at no point was there a magic switch where it was like, oh, now I'm atypical. I notice such a difference in my thoughts than I did when I was 10 pounds lighter. To draw this line in the sand of this is when it crosses over and becomes more important and more insurable and more lethal — that line is not a very good line. It always means there's an out group, and it always means that there's somebody who's not able to get treatment. So thinking

about how we draw those lines is really important in terms of health equity."

Harrop argues that the anorexia diagnosis could be structured as a spectrum, with weight as one component but not the predominant one. Physicians could look at a wider set of factors when screening, diagnosing and treating eating disorders. Eating-disorder diagnoses have overlapping symptoms anyway, Harrop says, and patients often cross over between illnesses. About 36 percent of people with anorexia develop bulimia at some point, and 27 percent of people with bulimia develop anorexia, according to one study.

Diagnoses affect not only how doctors and insurance companies categorize patients but also how people understand their own illnesses. Maxwell always bristles when she thinks about her own diagnosis, her mind snagging on the term "atypical." She sometimes flashes to a moment in junior high school when her teacher showed the class a photo of a fat man with a shirt that read, "I beat anorexia." It was meant to be a joke, and everyone laughed. She even laughed. But after a lifetime of bullying, Maxwell didn't want to be a punchline. Being labeled "atypical" added another layer of awkwardness and marginalization. The diagnosis seems to live in a no man's land of categorization. Many people who suffer from eating disorders say the

differentiation further perpetuates a social hierarchy. Just as living in a thin body comes with certain privileges, anorexia itself lives at the top of a kind of disordered-eating class system.

Mimi Cole, a therapist and podcast host, speaks openly about her past struggles with atypical anorexia. Ryan Pfluger for The New York Times

According to Mimi Cole, a therapist who had atypical anorexia and hosts [“The Lovely Becoming,”](#) a mental-health podcast, “A common belief among people with atypical anorexia — and I shared this too — is: I need to lose more weight so that I have anorexia, so that I can be sicker. I can meet criteria. I can have a real eating disorder.”

In late 2018, Maxwell decided to be more open about her eating disorder with friends and family and started posting about it on Instagram. Over the years, she included photographs of her younger self and shared memories of her decades-long journey. Sometimes it felt brazen and edgy, but also good. “I am fat and I have anorexia,” she wrote in a 2020 post. “And I don’t have to explain my body to you.”

These days, Maxwell’s inner landscape is very different than it once was. On a sunny Saturday afternoon in May, not far from where she lives in San Diego, she did something that would have brought her waves of anxiety in past years. She went to the beach. Amid the tinny jangle of an ice cream

truck, she unfurled her towel and sat down. Before she started her recovery, she would have spent her time at the beach worried about what she was wearing or not wearing, what she had eaten or would eat later and what other people were thinking or not thinking about her body. Fogged by this tangle of thoughts, she would miss the experience. Now she doesn't give those things much thought. On that Saturday, she watched her dog zoom around the sand and laughed with a couple of friends. Her mind was not floating above her body, dissociated.

Maxwell is choosing to recover as fully as she can, but it is not easy. After 19 years of going undiagnosed, she still suffers from some of the physical, mental and social costs of anorexia. Doctors are monitoring her recovery from long QT syndrome, an electrical issue with the heart that can turn into potentially fatal arrhythmias. (Long QT syndrome is a rare side effect of anorexia.) She also has an annual endoscopy to assess the slow healing of her damaged esophagus from years of vomiting. She has incurred mountains of debt from months of treatment.

She checks in with a doctor and a therapist regularly and texts photos of her meals to her dietitian as proof that she's eating three meals a day, a standard in recovery. She attends an eating-disorder support group, even though she has rarely seen another larger-bodied person there. She has also

started to cook for herself. But to be a larger person in this world is to be constantly reminded of how other people view your body.

Often when she posts about recovery and fat positivity on Instagram or TikTok, whether it's theatrically smashing her scale with a baseball bat or performing slam poetry in her car, a flurry of trolls rise from the backwaters of the internet to riddle her feed with insults and death threats. "You need a sign that says 'beware of pig,'" one commenter wrote. "Moo moo goes the cow," wrote another who created a handle (@sharon_maxwell_hater) expressly to bully her. "Society pities you because you're eating yourself to an early grave," another wrote.

But Maxwell has also received direct messages from people who have struggled in similar ways — they have never admitted to themselves, let alone their families or friends, how much they are suffering. "I just wanted to say that I am a fat person with an eating disorder who isn't yet in recovery but trying," one wrote. "Every day I have these crazy disordered thoughts and get into a spiral of how I'm not valid enough for recovery ... your content has been absolutely pivotal for me and I am so happy you exist."

Many people with anorexia describe the illness as a battle between two selves. One is a maniacal superego, hellbent on control at all costs in a misguided attempt to find safety. It

imposes perfectionistic rules and restrictions in Sisyphean pursuit of an unreachable ideal. Some feel it is intent on self-destruction. This self, which Maxwell calls the conceptualized self, enforces all the expectations of one's upbringing and the culture at large and sees the world in lifeless tones of black and white, like an old TV.

The second is what Maxwell calls the authentic self. For her, it's the self that spontaneously breaks into impromptu dance moves and wears T-shirts that read, "Don't be a butthole to yourself" and "Therapy is cool." This self has a penchant for gold glitter and animal print and signs up for a rec basketball team on a whim, something she would never have allowed herself to do before. She can eat strawberries or a sandwich or an ice cream cone in public. This self is no longer concerned with being quiet and obedient or apologizing for her existence. And, perhaps most important, she has no interest in making herself small.

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