

THE ARIZONA REPUBLIC

Eating disorders soared during the pandemic. In Arizona, demand for treatment remains high

Anxiety increased during COVID-19, and so did eating disorders. Getting help in Arizona can take weeks.

Callista Hostetler was 20 years old and doing Christian mission work in Amsterdam, far away from her friends and family in Arizona, when COVID-19 hit.

Feeling lonely and anxious, she began restricting her food intake and developed anorexia nervosa.

Gilbert resident Debbie Lesko, who shares her name with one of Arizona's Republican members of Congress, was in her 60s and in recovery from a longtime eating disorder in March 2020, when the World Health Organization declared a worldwide pandemic.

At home and worried about going outside, Lesko relapsed.

Tucson resident Bella Mendibles was 11 years old when she began attending school virtually because of COVID-19 restrictions. As the pandemic wore on, her parents noticed she was becoming increasingly anxious. Her anxiety amped up in 2021 after a beloved uncle died unexpectedly of COVID-19.

Eventually, Bella developed anorexia nervosa and became so severely undernourished that she required a feeding tube and months of residential care.

Federal data indicates that eating disorders, which are debilitating and can be fatal, soared during the COVID-19 pandemic, particularly among adolescent girls.

Recent interviews with Arizona health providers, patients and treatment facilities suggest that the problem has not gone away, even though the pandemic has waned.

Demand for eating disorder care in the state remains high, as does the complexity of patient cases, which may include not only mental health treatment but medical care for heart problems, hypoglycemia and malnutrition, providers say.

Because of high treatment demand and insurance barriers, treatment for eating disorders isn't always available to the patients who need it.

And treatment options are complicated by the fact that they often require a multidisciplinary team approach, rather than a single therapist, since eating disorders are the "true intersection of medicine and psychiatry," said Dr. Stuart Kaplan, who is medical director of the Rosewood Centers for Eating Disorders, which operates eating disorder treatment facilities in Wickenburg and Tempe.

Rosewood saw a jump in demand for care during the pandemic that has remained so consistent that leaders plan to open a third location within the next month, Kaplan said. The new 10-bed location will

be in north Scottsdale and is called Rosewood Scottsdale for Adolescents. It's a residential treatment center for kids of any gender ages 11 to 18 with an eating disorder.

Kaplan said Rosewood, which accepts multiple forms of insurance, including Medicaid, had waiting lists during the pandemic, and the waiting lists have continued to the present. Part of the reason demand for treatment remains at a high level may be that eating disorders, while still a source of shame for many people, became less stigmatized during the pandemic, he said, and as a result people with symptoms may be more willing to reach out for help.

"At Rosewood, the real tragedy is we have not been able to help as many kiddos as needed to be helped, specifically because of capacity," he said.

An estimated 9% of Arizonans, or about 650,000 people, will have an eating disorder at some time during their lifetime, according to a report on the economic cost of eating disorders published by the Harvard T.H. Chan School of Public Health. Nationally, about 10,200 people per year die because of eating disorders, the Virginia-based Academy for Eating Disorders says.

While early intervention is key to avoiding lifelong repercussions from eating disorders, families may not spot that a loved one has a problem because they miss the symptoms or they mistakenly believe only young white women are affected and that everyone who has an eating disorder is thin. Health providers have misconceptions, too, patients and eating disorder experts say. Emerging evidence suggests that eating disorder prevalence is increasing among men and boys and that eating disorders disproportionately affect transgender individuals.

Nearly everyone with an eating disorder has a co-occurring psychological illness — often an anxiety disorder, post traumatic stress disorder, mood disorders or obsessive-compulsive disorder, Dr. Cheri Levinson, founder of the Louisville Center for Eating Disorders and an associate professor at the University of Louisville, said during a journalists' web briefing about eating disorders earlier this year.

"And, so when you're treating an eating disorder, you really are treating not just an eating disorder, but also all of the co-occurring psychological issues that come along with an eating disorder," Levinson said. "And then, just another note here that death by suicide is significantly more prevalent in eating disorder populations compared to the general population. So, in addition to all of these comorbidities, there's also an increased risk for death by suicide."

People who have experienced eating disorders describe feelings of low energy, all-consuming obsession and a loss of pleasure in things they normally enjoyed, among other challenges. Starvation and irregular eating can impact the brain, the gastrointestinal system, fertility and metabolism, as well as bone and heart health. Some patients are unable to go to school, work, and take part in activities like sports. But since their eating disorder becomes a coping mechanism for underlying issues such as anxiety, it can be difficult to let go.

"You have the anxiety, you have the depression and sometimes you turn to food, whether it's restriction or increasing your intake," said Amy Girimonti, an eating disorder therapist at Embark Behavioral Health, which offers intensive outpatient care to people with eating disorders in the Phoenix area. "Very, very rarely do we treat eating disorders where there is not an anxiety disorder or heightened anxiety or some form of anxiety or depression. They usually do go quite hand-in-hand."

Girimonti said a rise in adolescent eating disorder patients during the pandemic could possibly be explained by the teens' loss of familiar routines and regular connection with friends, heightened anxiety, boredom, and possibly food insecurity at home.

"The increased rates of anxiety and depression attributed to the pandemic are staggering," she said.

Lindsey Wawrzyniak, who graduated this year with a degree in psychology and a minor in dance from Arizona State University, said she developed an eating disorder when she was a teenager. Her disorder got worse while she was a student at ASU. Suffering from fatigue and a low heart rate, she was hospitalized for anorexia nervosa in March 2019 and then spent two months in treatment at Rosewood Ranch in Wickenburg.

Wawrzyniak was in recovery and doing well when the pandemic hit in 2020. But as the pandemic persisted, she ended up relapsing and spent a lot of time trying to find help amid COVID-19 shutdowns and a spike in demand for care. She was on a waiting list before getting back into treatment at Rosewood in 2021. Wawrzyniak, 23, who was involved with a campus eating disorder recovery group, said some of her fellow students experienced an eating disorder for the first time during COVID-19.

"Stress is a big trigger for people that struggle with eating disorders and having a lack of control is really important. And I think a lot of us were feeling that way, just like feeling overwhelmed and feeling like we couldn't control things in the world," she said. "So it was easier to control the way we looked or the things we were doing to our bodies."

Wawrzyniak is active on social media and shares information about mental health and eating disorders with others. But spending a lot of time on social media can be extremely damaging — a fact that was magnified during the pandemic, she said. She recalled trying to stay strong in her recovery as she saw jokes about people gaining weight during the pandemic, sometimes calling it the "COVID 15."

To her those messages felt like a directive, that weight gain was shameful.

"That was really hard for me ... I know for a lot of my colleagues and friends as well, they really struggled with those messages, too," Wawrzyniak said.

Wawrzyniak is doing well now but some of her peers continue to battle eating disorders, she said.

Lisa MacDonald, who is the coordinator of nutrition services at the University of Arizona's Campus Health in Tucson, said she saw the number of students needing help with disordered eating increase during the pandemic, even though help was virtual and then hybrid for some time. The higher level of need has not dropped back to pre-pandemic numbers, she said.

The line between "disordered eating" and an "eating disorder" can sometimes be a little fuzzy and the clinical definitions of eating disorders are not expansive enough to include all the people whose disordered eating is negatively impacting their life, MacDonald said.

MacDonald says social media was a "breeding ground" for eating disorders, whether it was a focus on "before" and "after" pandemic photos, videos of meal preparation, and photos of what people were eating. Many of the students she's spoken with felt pressure to look "better" including thinner, after the pandemic, MacDonald said.

"We definitely saw numbers increase as well as acuity. Even now there's a much higher percentage of our patients who are coming in for some form of disordered eating, whether it's diagnosable or kind of blooming or teetering on that line of disordered eating to eating disorder," said MacDonald said.

Disordered eating may include fasting, skipping meals, dieting, a preoccupation with food and cutting out food groups, and can lead to full-fledged eating disorders.

Lesko, the Gilbert resident, maintains social media accounts she titles "Diets Don't Work" and encourages people to stop making weight loss the focus of their food choices.

Lesko, 67, said she was in a good place with her recovery in 2020 when the pandemic hit and she too was triggered by social media talk about pandemic weight gain, which she found "unbearable." Lesko said she quickly developed a mindset that if she were to gain weight, she'd be a failure.

"I had a definite relapse in 2020. ... The support groups that I was part of, we were all talking about it," she said. "Because I was not active, I wasn't doing anything to burn off the calories. Even though I had plenty of food in the house, it was off-limits."

One of the things that helped her get out of that dangerous mindset was having communal virtual meals with other people in recovery, she said.

The other thing that helped was her "Diets Don't Work" social media presence, said Lesko, who now practices what she calls intuitive eating and advocates reducing weight shame and weight stigma. She also had motivation to get better: she's come close to dying from her eating disorder several times, she said.

Lesko is in recovery from anorexia, which is intense fear of gaining weight leading to a restriction of food intake and a significantly low body weight in the context of age, sex, developmental trajectory and health. Other eating disorders include bulimia, which involves binge eating along with compensatory behavior like fasting, self-induced vomiting, excessive exercise, or use of laxatives, diuretics or other medications, according to the National Association of Anorexia Nervosa and Associated Disorders.

Another common eating disorder is called binge eating disorder, which typically involves recurrent episodes of binge eating often until feeling uncomfortably full without feeling physically hungry.

MacDonald said many of the students she sees fall into a category of "other specified feeding or eating disorders" because they don't fit the strict diagnostic criteria of anorexia, bulimia or binge eating. An example of an "other specified" eating disorder is atypical anorexia, where all the criteria for anorexia are met, except that the patient's weight is within or above the normal range.

Tucson residents Errin and Nick Mendibles sprang into action when they noticed changes in their 11-year-old daughter Bella's behavior during the pandemic. She was increasingly anxious and showed signs of obsessive-compulsive disorder. After her uncle died of COVID-19, Bella became increasingly afraid of the virus, and was particularly worried about any of her loved ones getting it.

Errin says that what she knows now is that her daughter's anxiety and OCD were precursors for an eating disorder, but the family was not aware of that at the time.

"In sixth grade, you know, it was completely online. So now they're not getting any socialization," Errin said. "Things got really, really hard at our house. And for us to not be able to find counselors, I mean, it was absolutely mind-boggling."

Bella's pediatrician was incredibly helpful, Errin said, but Bella needed more specialized treatment and the family was running into barriers. The counselors they found who were accepting new patients didn't take insurance and only wanted cash.

By the time Bella turned 14, she'd lost 40 pounds off an already small frame and was diagnosed with anorexia nervosa. She was also compulsively exercising, including sneaking out of the house to go running early in the morning.

"It was dire. ... And when you are talking about a mental health disorder, it's really hard to get help for pediatric patients," Errin said. "We had to leave the state in order to get her the care she needed."

When they tried to find care in Arizona in late 2022, one facility wanted \$15,000 upfront and another said there was a six-to-eight-week waiting list, but the Mendibles say they were worried that without help Bella would not live for another six to eight weeks.

Bella ended up getting inpatient treatment for two months in Denver at the Eating Recovery Center. Her family took her to San Diego for a family-based partial hospitalization program at the University of California San Diego Eating Disorders Center that lasted nearly three months, her mother said.

The Mendibles family say they are fortunate that their insurance covered both stays after they paid a \$5,000 deductible, and that they could afford to visit Bella on a weekly basis in Denver and to live for a brief period in San Diego when she was in treatment there.

They've since launched a nonprofit peer processing group for parents of kids with eating disorders called Bella Vita Tucson because they'd looked for such a group when Bella became sick, but couldn't find one. The group, named for their daughter, means beautiful life in Italian, and Errin said she hopes it will be able to help families not only with emotional support and referrals but with costs if kids are in treatment away from home. Her ultimate goal is to build an inpatient eating disorder treatment center in Tucson, she said.

"It's just a sad thing that these kids are going through," Errin said. "And then the parents, you know, we are all just sitting there trying to figure it out."

Bella, now 14, is in recovery and will start high school this year.

"She is getting better but she is not better," her mother said. "And I think that's every eating disorder patient. They will always be striving to get better but ultimately it takes a lot to be better."

Phoenix Children's Hospital has seen not only a rise in eating disorders since the pandemic, but also in the complexity of cases, John Brewer, the hospital's vice president of behavioral health, wrote in an email. The increase has led hospital officials to improve their eating disorder screening process and also to improve connections to community resources and specialists, he wrote.

While anorexia, bulimia and binge eating are common, Phoenix Children's is seeing a rise in another eating disorder called avoidant restrictive food intake disorder, or ARFID, Brewer wrote. ARFID is similar to anorexia except that the patient does not have distress about body shape or fears of fatness.

Arizona has barriers to getting kids into higher levels of treatment for all kinds of eating disorders due to waiting lists at live-in facilities and insurance obstacles, among other things, Brewer wrote. While Phoenix Children's can provide medical stabilization, there are other key components to treatment, including family-based therapy, intensive outpatient treatment and residential care, he said.

One kind of eating disorder treatment that Brewer said Arizona is missing is a "partial hospitalization program" for kids like the one Bella attended in California, where patients can go for treatment during the day and have at least two meals but return home for the evening.

Kaplan, the medical director at Rosewood, says there aren't enough services in rural areas in Arizona or nationwide where eating disorder patients can get "step down" treatment after being in 24/7 care. The goal is to have treatment that's within a "reasonable commute" of patients' homes, no matter where they live, he said.

Providers say earlier intervention is always better and one of the first places where a problem might get noticed is at a primary care doctor's office. But it takes an "astute" primary care provider to ask the right questions and spot an eating disorder or disordered eating because patients so frequently try to hide it, said Dr. Deborah Fernandez-Turner, the deputy chief psychiatric officer for CVS Health.

Patients with eating disorders often seek medical care for symptoms such as fatigue, dizziness, nausea and stomach problems.

"I'm tired all the time, I'm kind of dizzy, I just don't feel good, I'm not thinking well — all of those can be indicators of not getting enough nutrition," Fernandez-Turner said. "There are a lot of practitioners who are working at expanding their skill for this particular population. ... The earlier you catch it, the easier it is to treat."

Too many health care providers are still lacking awareness of eating disorders, said Girimonti, the eating disorder therapist at Embark Behavioral Health, who also is a therapist in private practice.

Girimonti, who believes medical schools should include more eating disorder education, said her patients can often vividly recall hurtful comments that health professionals made about their weight, even years later. She gives out cards that patients can share with providers that request practitioners not to talk about the patient's weight unless it's necessary.

"Often (medical) staff isn't aware of eating disorders and they'll just kind of blurt out a client's weight, which can be really triggering," Girimonti said.

One of the most difficult aspects of getting over an eating disorder is body image and moving on from the disorder, because it frequently becomes an identity that occupies most of the patient's day, Girimonti said. Some patients even get nostalgic for being sick or they are afraid to move on because they got compliments on their body when it was undernourished.

Lindsey Wawrzyniak understands that struggle. She has a picture of herself that was taken in early 2019, shortly before she was hospitalized. She was sick and in need of treatment and remembers feeling extremely unwell. In the photo, she's in a leotard and doing a dance move. Her body looks emaciated and her eyes have a glassy, faraway look.

"I received compliments on my body and how 'disciplined' I was with my diet and exercise routine," she wrote in an email, recalling the photo. "This praise and approval from others only made things worse. ... When my identity was based on what other people thought of me, I felt the need to keep doing what I was doing even though it was unhealthy."

Wawrzyniak says food is a part of her life that will always be important but her day-to-day existence no longer revolves around eating and her body — a freedom that allows her to experience life in a way she couldn't during the years when was ill. She recently accepted a professional dancing job and hopes to one day open her own dance studio and incorporate mental health and body image classes for dancers and athletes. That's something she wishes she'd had as a young dancer.

Callista Hostetler, now 23 and living in Peoria, said she tried to get help for the anorexia she developed in Amsterdam during the pandemic, but the programs in Europe were backlogged.

So she returned home to Arizona in 2021 and spent 70 days at Rosewood. She got married, is now working part-time and going to school to study psychology. She's still getting help for her eating disorder.

"Honestly what got me through was being with family again and just being in a situation that was familiar. And then obviously the pandemic calmed down, so that was easier to cope with," Hostetler said. "Just being so far away from everything, I think that was one of my main triggers. ... And then it became this whole thing of being stuck in my own mind.

"I definitely will be taking care of my mental health for the rest of my life."