A grown-up approach to treating anorexia by Carrie Arnold

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Adults with anorexia often have distinctive traits that lock them into a destructive relationship with food. Carrie Arnold discovers how those same traits could help them escape it.

Heather Purdin had run out of options. Aged 33, she had been suffering from anorexia nervosa for more than two decades and her weight had plummeted to that of a small child, an all-time low for her. Her case worker, out of frustration and desperation, suggested hospice care as a way to spend her remaining days in relative comfort. But for the first time in years, Heather was sure of one thing: she desperately wanted to live.

Treating anorexia, which is characterised by self-starvation and an inability to maintain an adequate body weight, seems absurdly simple on the surface: just eat and gain weight. It’s something Heather and the millions of others afflicted by eating disorders have heard countless times. The problem is that it’s never that simple. Heather has long since lost track of the number of times she has been admitted to hospital for low body weight, electrolyte imbalances caused by starvation or self-induced vomiting, or thoughts of suicide. In hospital she gains weight, but as soon as she is discharged she promptly returns to her old ways and loses what little weight she has gained. And so for more than 20 years, she has remained hopelessly, incurably, stuck.

Up to one in five people with chronic anorexia may die as a result of their illness, either due to the direct effects of starvation and malnutrition or due to suicide, making it thedeadliest of all psychiatric disorders. Although scientists have made tremendous progress in decoding the underlying biology of eating disorders and in finding ways to intervene in cases of teenage anorexia before the disorder becomes chronic, this hasn’t translated into effective treatments for adults like Heather.

A chance posting on Facebook last fall, however, brought Heather the first breath of hope she had felt in years. In Ohio, there was an experimental five-day intensive programme to help adults with anorexia. What made this one different was that it used the latest neurobiology research to mould its goals as well as how its treatment was delivered. And since research confirms that most patients struggle to make changes to their entrenched behaviours on their own, patients also had to invite up to four support people to join them on the residential programme. Heather asked her father and her sister, and began raising the funds to fly them all to Ohio.

“I need this to work,” she said. “I have nothing else to try.”

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Despite its reputation as a quintessentially modern disorder, anorexia is nothing new. Historians believe that many of the ‘fasting saints’ of the Middle Ages had anorexia. The first medical report of the illness appeared in 1689, written by London physician Richard Morton, who described it as “a Nervous Consumption” caused by “Sadness and anxious Cares”.

Even as recently as the 1970s, anorexia remained something of a clinical oddity – a disease that doctors rarely saw, let alone had a clue how to treat. When psychologist Laura Hill saw her first anorexia patient at a university counselling centre back in 1979, she had never even heard of the disorder: “Her father was in the science department there and I had to ask him what anorexia was,” recalls Hill. “He told me she was unable to gain weight, afraid of food.”

Rates of anorexia had been steadily climbing since the 1950s, but it wasn’t until the death of singer Karen Carpenter in 1983 that the disorder became a household word. She died from heart failure due to anorexia nervosa, and all of a sudden newspaper stories and after-school TV specials began to feature teenage girls “dying to be thin”. Besides highlighting the spectacle of a healthy, attractive young girl’s determination to starve herself, the storylines usually focused on the family dysfunction that psychologists believed lay at the heart of the disorder. Parents were told not to be the food police, that anorexia was a misguided search for control. Only when they let their child be fully in control of their own life would the anorexia resolve.

Psychiatrist Walter Kaye wasn’t convinced. Despite not having done research into eating disorders before, he had been asked to help finish an anorexia study for the US National Institutes of Health in the early 1980s. While talking with the participants, he noticed something unusual.

“I was just kind of struck by how homogenous the symptoms were,” he says. Because the patients seemed so similar in terms of symptoms and temperament, he believed there had to be something in their biology that was causing anorexia – and he dedicated himself to finding out what it was.

In the early 1980s, anorexia had been seen by the medical community as a deliberate decision by a petulant teenage girl: she was selfish, vain, wilful. Since she had chosen to become ill, she simply needed to choose to get better. She needed to become a fully formed individual, to separate from her family and rebel against the cultural ideal of thinness at all costs.

How I manage my eating disorder

Carrie Arnold shares her experience of more than 15 years of anorexia.

Scientific research by Kaye and others, however, exploded every aspect of this stereotype (not least that anorexia only affects girls) and completely changed how we think about the condition. Psychologists like Laura Hill had to rethink their whole approach: “Many times, I want to call up all my old patients and apologise for getting so much backwards,” she says.

Hill began to keep a file full of notes about what she thought was causing anorexia, what her patients believed, what seemed to work and what didn’t. After a few years, she entered a PhD programme to better help her patients. But even with several research articles to her name and, ultimately, decades working at the forefront of treating and researching eating disorders, she realised that the treatment advances weren’t reaching adults with anorexia. She wasn’t the only one. Across the field, psychologists, psychiatrists and dietitians have noted that treatment outcomes for adults with anorexia remain abysmally low. Less than half recover fully, another third show some improvement, but the rest remain chronically ill.

“They go for many years, and they’ve relapsed over and over again, and they have the highest risk of dying,” says Kaye. “I think all of us are feeling that this is a serious, often deadly disorder for these people, and we don’t have good approaches, and we don’t understand enough about the causes.”

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For adolescents with anorexia, a ground-breaking treatment developed at the Maudsley Hospital in London in the 1980s called family-based treatment (FBT) has significantly improved short-term recovery outcomes. It puts parents temporarily in charge of making food and exercise decisions for their child and places a priority on normalising weight and eating habits. In a randomised clinical trial published in 2010, around half of teens treated with FBT met criteria for full recovery after a year, compared to 23 per cent of teens receiving standard treatment.

Nothing has been remotely that successful for adults with anorexia, and there’s no easy explanation as to why. One reason may be that adults have simply been sicker for longer, says Angela Guarda, Director of the Eating Disorders Program at Johns Hopkins University: “The longer you have anorexia, the more anorexia creates physiological changes in the body and the brain that then create a self-sustaining cycle. You do it today because you did it yesterday, no longer because you decided to go on the Atkins diet when you were 15 or because your coach said something to you or you broke up with a boyfriend and you decided to lose weight. It’s no longer about that.”

As well, many people with anorexia don’t grasp that they are, in fact, sick. While parents generally sign their children into treatment, that power vanishes when the child turns 18. Adult patients can also stop treatment if it gets too difficult – and it often does, because challenging the behaviours associated with eating disorders can create tidal waves of anxiety. A long-term, chronic eating disorder often ends up alienating friends and family, the very people who tend to push their ill loved one into treatment and support them through the recovery process.

Clinicians, like their patients, are desperate for something better, some way not only to help adults with anorexia normalise their eating and gain weight, but also to help them stay well. “In anorexia, you get their weight up and they go home straight from inpatient [where] they’re fed from a tray, and they’re expected to know how to eat in a restaurant, eat in a cafeteria, eat in social settings, when they haven’t been eating with anyone for a decade,” Guarda says.

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On a warm spring weekend in 2006, Laura Hill stopped in the middle of mowing her lawn. She had spent the morning reading one of Walter Kaye’s articles on the neurobiology of anorexia, and was familiar with how Kaye and his colleague Stephanie Knatz were beginning to use neurobiology in designing new treatments for adolescents. It occurred to Hill that she could do something similar for her adult patients.

She dashed inside to grab a pad of paper and a pencil, where she scribbled a few notes before returning to her lawn. Several passes later, she had another insight and again stopped mowing to add to her notes. This went on all afternoon. It took until dusk to finish the mowing, but by then, as well as a neatly cut lawn, Hill also had the outline of a new type of adult anorexia treatment that would harness the strengths of people with the disorder and try to compensate for their weaknesses.

She continued to work on the outline, asking her patients at the Center for Balanced Living in Ohio for input on what they found helpful. A few years later, she teamed up with Kaye and Knatz, who further refined the idea based on their experiences at the University of California, San Diego. There, they had had remarkable success with a five-day intensive FBT programme for adolescents. Rather than seeing someone once a week, which might not be enough to be effective, or taking them away from their family and putting them in an artificial environment for a residential programme, they had insisted that the family come and stay too. Encouragingly, some young adults – living at home or supported by their parents – had also taken part, suggesting that this format could work with an older crowd as well.

“As opposed to having people step in for an hour and talk about what happened over the week, we’re actually seeing what happens live, in vivo. That gives us the possibility to intervene in vivo, as opposed to coaching people on what they should do ‘when circumstances come up’,” says Knatz.

In 2013, Hill, Knatz and Kaye applied for a grant from the US National Eating Disorders Association to fund a pilot study of what they called Neurobiologically Enhanced With Family/Friends Eating Disorder Trait Response (NEW FED TR).

Every aspect of the programme was based on what researchers understood about what happens in the brain of someone with anorexia, the goal being not just to improve treatment but also to reduce blame and guilt among sufferers and families. To that end, NEW FED TR would involve care givers and loved ones as an integral part of treatment, creating a team that could work to fight the eating disorder together. Responsibility for recovery would remain firmly in each client’s hands, but some aspects of recovery that tend to be sticking points for adults with anorexia could be outsourced to their support people as needed.

On an unusually mild Monday morning in December 2015, Heather Purdin was fiddling with the ponytail securing her dark brown hair, just as she always does when she’s nervous. It was a short drive from the hotel, across the freeway interchange to the back of a wooded business park. Her body mass index (BMI) was very low now – all muscle and softness stripped from her body, leaving only sinew and bone. A baggy shirt and scarf couldn’t conceal how ill she was. But she was not on her way to a hospital or a hospice. Flanked by her father, sister and best friend, she entered the Center for Balanced Living to take her place on the successfully funded pilot of the NEW FED TR programme. And despite all her fears, a giant grin lit up her face.

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It looks like any other kitchen. Long, grey countertops line one wall and an island; there’s a large stove, a sink and a fridge. Beau Barley, a tall, thin 20-year-old with bleached blond hair and a two-day-old beard, is cooking an omelette for breakfast while his parents prepare their own meals. It could be breakfast at any home in America, except that Beau is at the Center for Balanced Living, on his second day of the NEW FED TR programme.

“Okay, clients, check in with your supports to make sure you’ve got enough to eat,” calls the programme’s dietitian, Sonja Stotz. She listens in as Beau shows his meal of eggs, toast, butter, milk and fruit to his parents.

Like around half of those with anorexia, Beau suffered from obsessive–compulsive disorder (OCD) as a child,

having to turn off lights in a certain way and avoid all the cracks on the sidewalk. Every time he heard a siren, he had to call his mom because he thought she had been in an accident because he didn’t do one of his rituals right.

Always sporty, his anorexia started with a simple desire to be a better runner on his high school cross-country team. He amped up his mileage, running longer and longer each day and eventually training year-round. The sport he loved became a compulsion. But overtraining eventually took a toll and he was sidelined by a severe stress fracture. His only thought as his leg was being X-rayed in the hospital was that he needed to cut back on his food if he wanted to stay in shape for next season. As his mother pushed him out of the emergency room in a wheelchair, she asked him what he wanted for dinner. “A salad,” he replied.

From there, Beau became more and more obsessed with eating ‘healthy’ and returning to running. At first, his weight was stable. But as his running obsession returned, his metabolism kicked in. Always somewhat slender, his weight plummeted. In the summer before he started university, he went through his first formal treatment programme at the Center for Balanced Living, attending group therapy during the day, eating his meals at the centre and returning home every night. Things started to look up, but Beau relapsed during his first year at university. Over the past summer and fall, he has tried to make progress against his eating disorder, but the exercise compulsion is cemented in place. When his mother called the centre to see if he could return, they recommended NEW FED TR. Beau eagerly signed up and now here he is, showing his parents what he has cooked for himself this morning.

“Are those all your exchanges?” his mother asks. NEW FED TR uses a meal plan that assigns each individual a certain number of choices or ‘exchanges’ from each food group for every meal and snack.

He indicates that it is, telling her how the food on his plate adds up to his prescribed meal. Satisfied with his choices, Stotz moves on to assist one of the three other families in the kitchen. Beau’s family sit down at the table and, as breakfast begins, Hill and Stotz suggest fun games to play as a distraction, to decrease the anxiety all of the clients feel around eating. The less anxiety they feel, the more likely they are to successfully complete the meal, which serves as their medication.

Stotz points out that her job is selling her patients on the idea that they need to eat more and exercise less, the very opposite of what most dietitians do. “I should go into sales,” she laughs.

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In the morning sessions, Hill gives the clients and their families a crash course on eating disorder neurobiology. Eating disorders typically begin in adolescence, and anorexia is no different. Although the exact circumstances that trigger the onset of anorexia aren’t clear, nearly all cases begin when a person fails to meet their energy needs, placing them in a state of what researchers call negative energy balance – burning more calories than they eat. For some, a weight-loss diet precipitates the eating disorder; for others, it’s increased sports training, a growth spurt, an illness, decreased appetite from stress, even new braces.

For most people, being in a negative energy balance is profoundly uncomfortable. That’s why dieting often makes people impulsive and cranky, ‘hangry’ even. But those with a predisposition for anorexia have a completely different experience. Starvation makes them feel better.

Kaye’s work with women who have recovered from anorexia nervosa found unusually high levels of the neurotransmitter serotonin in the cerebrospinal fluid that bathes the brain, and he believes these levels were likely also present before the onset of anorexia. Although low serotonin levels are linked to depression, high serotonin levels aren’t good either, as they create a state of chronic anxiety and irritability. As many as three-quarters of those with anorexia had suffered from an anxiety disorder before their eating disorder began, most commonly social anxiety and OCD. It is this anxiety that Kaye believes makes some people much more vulnerable to anorexia.

The body synthesises serotonin from the amino acid tryptophan, which we get from our diet. Eat less food and you get less tryptophan and hence less serotonin. For people predisposed to anorexia, therefore, starvation reduces the anxiety and irritability associated with their high serotonin levels. Mission accomplished, or so it seems. The problem is that the brain fights back, increasing the number of receptors for serotonin to wring every last drop out of the neurotransmitter that is there. This increased sensitivity means that the old negative feelings return, which drives the person to cut back even more on what they’re eating. Any attempts to return to normal eating patterns wind up flooding the hypersensitive brain with a surge of serotonin, creating panic, rage and emotional instability. Anorexia has, in effect, locked itself into place.

Heather Purdin and her team see this first-hand as Hill asks the different groups of clients and supports to use yarn, taken from Hill’s massive collection of weaving supplies, to wind the client’s hands into place. Heather’s team rapidly pin her hands and arms in front of her face. This, Hill says, is the anorexia in action. Heather is now as stuck physically as she is mentally. Getting her functioning again means weaving her supports into her mental ‘loom’. Here is where the team struggle, especially when Hill asks Heather what she is going to do differently. In sheer frustration, she slams her knotted hands onto the table in front of her.

“It’s not working,” she wails. “I can’t change.”

The tears start and it doesn’t seem they will ever stop. It is, however, her lightbulb moment.

“I realised I wasn’t completely crazy,” Heather says later. “It was a huge relief.

It is real and I’m not making it up and I’m not a complete loser.”

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Recovering from anorexia, Hill says, is like learning to navigate around landmines. They can be deadly, and they can derail recovery. One of the biggest struggles for people with anorexia is making decisions: a first-year university student on the programme, who asked not to be named, admits that she can stand in front of the fridge for hours trying to decide what to have for lunch. Frustrated, she often shuts the door without eating anything.

Hill rounds everyone up and asks them to toss their treatment binders into the centre of the room. One by one, the clients are asked to close their eyes and walk across the room without bumping into anything. Not surprisingly, no one can do it. But when they ask a family member to guide them, they get safely to the other side. In real life, this could mean the university student asking one of her parents to pack her lunch for her if she becomes too anxious to make a healthy

decision.

“People with eating disorders have many amazing qualities, and like anything it has both positives and negatives,” says Hill. The goal of the programme is to make these traits work for an individual as much as possible, and to enlist loved ones to fill in for the parts of the brain that might not be working properly.

The exact details of this are hammered out by each family throughout the week in the Recovery Support Agreement. Skipping meals or snacks or not gaining weight as appropriate could result in consequences that are agreed in advance, like leaving university or eating more meals with supports.

“It’s helpful for people with anorexia because they like rules, they like structure, they don’t like the unknown, so they have a pretty good idea of what’s going to happen if they’re not able to eat and gain weight. And our data is suggesting that may be a useful approach,” says Kaye.

A 2003 study identified five personality traits that increased the risk of developing an eating disorder: perfectionism, inflexibility, having to follow the rules, excessive doubt and caution, and a drive for order and symmetry. Other studies have found links between anxiety, perfectionism and anorexia. Adults with anorexia get stuck on details and have trouble zooming out to see the big picture, which can make it difficult to make decisions. As well, they have difficulty mentally switching from one task to the next.

For too long, says Hill, eating disorder professionals have been focusing on these traits as weaknesses when that’s not true. To succeed at scientific research, for instance, obsessionality and attention to detail is almost a must. Since people with anorexia use rules and routines to ‘succeed’ at their eating disorder, they can also learn to use them to succeed at recovery. It sounds like a small shift, but for anorexia sufferers like Heather and Beau, it makes all the difference in the world.

“Make your quirks work,” Heather quips with a smile.

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“Ew, don’t eat that,” says the mother of the first-year university student. She isn’t providing feedback at mealtime now but playing the role of the insula, a region of the brain that is sensitive to disgust. Other participants role-play other regions in a re-enactment of how the brain makes decisions around food.

In healthy individuals, determining what and how much to eat is controlled by a variety of factors, including what’s available, how much it’s liked and how hungry the person is. Not so in anorexia. Kaye’s work using functional magnetic resonance imaging (fMRI) of the brain has teased out other important details. Unlike most people, whose brains respond strongly to rewarding things such as sweets, people with anorexia are generally far more sensitive to punishment (the removal of something pleasant) than reward.

Another study found that the brains of women who had recovered from anorexia responded significantly less to sugar water than healthy controls, and they found sweets less rewarding when hungry. Kaye says these results may indicate how they are able to continue starving even while food is plentiful, since people with anorexia find food less rewarding and thus have less motivation to eat. Tests also showed a preoccupation with future harm at the expense of what might be needed in the present moment.

“One reason that people with anorexia are able to starve themselves is that when they get hungry, the parts of the brain that should be driving reward and motivation just aren’t getting activated,” he says.

So when it’s time to role-play the ‘anorexia brain’ considering whether or not to take a bite of banana, those people playing brain regions responsible for reward (the feeling of ‘yum!’ when you eat a piece of chocolate cake) are quiet, while the brain areas responsible for worry kick into overdrive. The result is that no one in the room can hear the small, quiet part of the brain telling the person with anorexia it is okay to eat the banana.

Hill plays an audio recording of one of her former patients re-enacting the anorexic thoughts that tormented her while she ate – it is an endless stream of “I can’t eat this. I’m going to get fat. I’m ugly. I’m disgusting. I’m weak. I hate myself. I can’t do this. I’m so pathetic, just pathetic, a weak pig.” It goes on for more than ten minutes.

Parents, many of whom had walked into the programme frustrated and angry at their child’s seeming refusal to eat, hear the recording and the sheer amount of ‘noise’ that their children endure and their anger dissipates.

“I get it now,” Beau’s mom says, dabbing at her eyes with a tissue. “I get it.”

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Heather’s week at the NEW FED TR programme has been life-altering: “For the first time, someone got what I had been saying all along, that I had a biologically based brain disorder,” she says. “They worked with me instead of against me.”

By December 2015, nearly 25 families had participated in NEW FED TR, and more pilot groups are in the works. Feedback, Hill says, has been uniformly positive, even from those with anorexia – pretty rare for a treatment programme that requires a person to face their deepest fears six times a day, eating three meals and three snacks. It’s too soon to say whether the programme has been effective in helping adult anorexia sufferers move towards recovery, but for Heather it marks the first time she has actually believed in her own ability to get better.

For the first time in 20 years, she says simply, “I have hope.” And with that, she heads to Trader Joe’s to buy ingredients for a Christmas feast she is hosting for friends and family. It would have been unimaginable last year, but now she hopes it will become a tradition that will continue for a very long time.

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