Give food a chance:

A new view on childhood eating disorders

Dr. Julie O'Toole

About this book

Give food a chance arises from the clinical experience of Dr Julie O'Toole, MD, MPH, over more than a decade, of treatment for eating disorders in children and young adults. Dr O'Toole rejects former theories that claim such disorders are caused by poor parenting, issues of control, rejection of adulthood, or society's oppression of women. Instead, the author's thesis is that anorexia in particular is a chronic, highly heritable brain disorder. The book is written for any parents or professionals who care for children with eating disorders.

About the author

Dr. Julie O'Toole attended Reed College and University of Washington, then received her MD from The Technical University in Aachen, Germany. She completed her pediatric training in Honolulu, Hawaii. Her work involves the study of child behavior, especially in regard to eating disorders. On the side she is a botanist, gardener, and writer. She currently practices medicine in Oregon, while engaging in important medical research with colleagues around the world.

"There are books one recommends to strangers, and those one presses on friends. I will be showing Give food a chance to my friends and enemies alike, and I look forward to the discussion it will initiate. O'Toole presents a conflict for all of us: We can either remain stuck in old and ineffective ideas or have the courage to reject them."

—Laura Collins Lyster-Mensh, Executive Director
F.E.A.S.T.
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1 Introduction

1.1 Our patients are our teachers

In 1980 I graduated from medical school in Aachen, Germany as an American "foreign student." We had classes in every imaginable subject, the German medical system being extraordinarily thorough: In legal medicine, in forensic medicine, in psychological medicine, and in the more usual areas as well: Pharmacology, neurology, pediatrics, surgery, and so on, covering diseases and conditions common and rare. But no one taught us about anorexia nervosa. We had a classmate who was afflicted. Everyone knew it—it was obvious: She was skeletally thin, the veins in her arms stood out like ropes, her lackluster hair clung thinly to her head, she rode around campus on her bike furiously, exercising, exercising, always exercising, and she was a fantastic student. But she was shunned socially, and the young male medical student she admired was appalled at the deranged appearance she found acceptable.

In 1985 I finished pediatric residency in Honolulu, Hawaii, and returned to the mainland to begin the practice of general pediatrics. As a woman doctor I seemed to pick up several adolescent patients with eating disorders, but I was at a loss to really know how to help them. I listened to them, I pleaded with them, just like everyone else. I referred them to psychiatrists. I rarely heard from or about them again. In 1991 I joined a large pediatric practice in Portland, Oregon, and eventually I established an adolescent

medicine practice there. At first there were a few patients with anorexia in this young practice, and gradually there were more. And more. Frustrated colleagues heard I was willing to take on the care of these young sufferers, deemed hopeless by many, and sent them my way.

One of the most challenging cases I ever treated dated from that era: LT, a 14-year-old girl who weighed 68 pounds. I had known of LT; she was a longtime patient of one of my partners, an emaciated, infantilized, difficult child, and I had carefully avoided getting involved. My partner's treatment consisted of reminding her that starving children in Asia would be happy for her share of food, and actually went so far as to recommend a trip to India to her desperate parents. I was sure I had nothing important to offer, and so continued to avoid getting involved. But one evening, when I was the doctor on call, she came in fainting, confused, and with a dangerously low heart rate. Oh, yes, and angry!

Clearly, whoever walks in the door when you are on call is your responsibility. I promptly put her in the hospital. The nurses were appalled both at the hospitalization and the patient. She refused food, of course. She threw food, she cursed the nurses, she had to be physically restrained, we couldn't get her psychiatrist to come and see her in the hospital, she pulled out her IVs, she pulled out her NG tube, spilling her food replacement all over the floor. She howled. This did not make me popular with the hospital staff. I did not know what to do. We had to impose draconian rules on her, which is not the usual *modus operandi* for a pediatrician. We are the good guys. We *like* being the good guys. It was a nightmare, and when she left the hospital, she went right back to starving and exercising, assiduously working off every calorie we had delivered, while continuing with her therapist and nutritionist as before: Arguing, bargaining, and doing whatever the hell she wanted. It

was demoralizing, frightening, and discouraging—yet LT was my teacher.

LT, and all the patients whom it has been my privilege to treat after her, were my teachers. Through their suffering and my early abortive attempts at help came the one great insight about their disease that was to change everything for me: Anorexia nervosa is a brain disorder, an organic (biologically based) disease like diabetes or stroke. Neither a lifestyle choice nor a result of poor parenting, it looks organic, it acts organic, it is organic. Furthermore, if anything, it acts most like those great human diseases such as syphilis and tuberculosis whose clinical symptoms, regardless of the patient's age, sex, or nationality, are so characteristic as to be virtually "pathognomonic," a doctor's word for unmistakable. Like rashes, coughs, and bleeding, its manifestations cut right across developmental stages and ages. In most cases, the 10-year-old boys report the same thoughts and concerns as the 19-year-old girls; their delusional beliefs are the same, their core behaviors eerily the same, as if cloned.

This observation flew in the face of accepted psychiatric dogma. Psychiatrists taught that anorexia nervosa was caused by enmeshed mothers and distant fathers. It was conceptualized as a flight from maturity, a manifestation of Western beauty ideals in women, a feminist issue, a family issue, a class issue. Listening to my patients, peering into their families, treating them, this made about as much sense to me as a flat earth or leeches for headache. I found it curious that "scientific" papers were written detailing what the patients said were the "reasons" they had anorexia nervosa. Their medical beliefs were held forth as scientific dogma: "Food was the only thing I could control about my life;" "I didn't want to become my mother;" "I didn't want to become a sexual being." Hadn't anyone read medical history books? Asking patients why they believed they

had acquired a disease was a notoriously poor way of determining etiology (cause), and relying on popular opinion was even less reliable. If you had suffered from leprosy in the twelfth century and someone had asked you why you thought you had it, you would almost certainly have replied something to the effect that it was a punishment from God for your sins, and your entire society would have supported you in this belief. Yet it was nonsense. Didn't anyone in psychiatry remember *refrigerator mothers,* the purported cause of autism or *the ulcerogenic personality,* the purported cause of ulcers? That we had been taught in medical school!

I was tremendously helped in the realization of the neurobiological nature of anorexia nervosa by the fact that I was a medical doctor yet not a psychiatrist. I did not have a great backlog of learning to divest myself of. I had been taught virtually nothing about it, which allowed me to see it with open eyes, without preconceived notions. Furthermore, my livelihood did not depend on a series of beliefs about human functioning (such as psychoanalysis) that would have stood in the way of a new treatment paradigm.

As I began to learn about the mechanics of human starvation and re-feeding, I traveled as far as I could to see what was known. Surely I could not be alone in this belief? I went to international eating-disorder conferences throughout the 1990s and made myself mighty unpopular by asserting that, in the twenty-first century, this anorexia, this rare brain disorder, needed reframing. When I spoke up at a conference in London, I was angrily denounced for suggesting we look at anorexia nervosa as a disease not unlike type I (insulin-dependent) diabetes, and as a condition where the patient's underlying genetic vulnerability was acted on by an unknown environmental trigger, initiating a cascade of (predictable) behaviors and symptoms, one that—like type 1 diabetes—could

be treated but not eradicated. I pointed out that formerly, type 1 diabetes had also been laid at the feet of mothers feeding their children too much refined sugar. This concept was dismissed firmly by several of the psychologists present. One famous British psychiatrist insisted there was not "one shred of evidence" for a genetic basis to anorexia, and the moderator "reminded" me that it was well known that too much sugar did cause some diabetes!

Lonely in my belief, and with the responsibility for many young patients and their families, I read everything scientific I could get my hands on. I corresponded with overseas physicians and researchers of eating disorders and allied scientific fields. For a while, it appeared the only people who agreed with me were geneticists and veterinarians who studied feeding behavior in mice and rats. I was privileged to find an ear in Roger Cone at Oregon Health Sciences University studying the control of weight in humans and other animals. Working in an atmosphere entirely unencumbered by outdated medical beliefs, and believing only what they could support with data, his team found my approach not odd at all. Genetic vulnerability interacting with environmental "triggers" or agents seemed likely to be the model for most human disease.

In 1998 I went to Stanford University as a visiting scholar to learn what they knew about childhood eating disorders. Iris Litt, a leader in the field of adolescent medicine, acted as my mentor. Stanford was a breath of fresh air and a great opportunity to learn. Although, at the time, my adolescent medicine colleagues there did not share my belief in anorexia nervosa as a brain disorder pure and simple; they had begun to perfect the art of convincing insurance companies that it needed to be treated on a medical (not psychiatric) floor and that no success was possible unless and until weight restoration was given absolute priority. Today this may sound like a given, but throughout the twentieth century

and even now, in many places, people who suffer from anorexia nervosa are given years of psychoanalysis or other psychological treatment in the absence of weight restoration. The prognosis with this approach was often poor because physicians had abdicated the field to psychologists and nutritionists who did not focus—no, insist—on the core fact of successful treatment: *Without weight restoration you get nothing.*

In my opinion, bargaining with a brain-starved individual about food and calories and grams of fat has always been worse than useless, especially in children. No doctor would argue with a child about the dose of antibiotics in a case of meningitis, nor surgeon allow a child to tell them how (and if!) a ruptured appendix should be removed, yet respected practitioners withheld lifesaving re-feeding because the child "was not ready to accept it" or was not yet "vested in their own recovery." What nonsense! This disease, this anorexia, with a reported mortality (death) rate of 10%, worse than many diseases considered severe, was allowed to lay waste to a child's body, sometimes for years. Parents read the psychological press about parents being the cause; they were told to "butt out," to leave the topic of food to the psychologist and the patient to deal with. They were told that without psychological acceptance on the patient's part, no amount of "force feeding" would be useful. Desperate, saddened, they watched as their child dwindled away. Pediatricians, also having abandoned the field to psychiatrists and psychologists (between whom they made little distinction), washed their hands of the responsibility for re-feeding and accepted the belief that the parents were the root cause of the disorder.

Armed with the courage my colleagues at Stanford had fostered and the vocal support of my husband Steve, I returned to Portland, left my general pediatric practice and founded the Kartini Clinic for children with all conditions of disordered eating. For the

first few years we focused on building a multidisciplinary team. No one doctor could do it alone: Diseases of the brain are too severe, the brain being the core of who we are; too affecting of family, school, and social functioning for any approach but a holistic one to work. To keep the focus on weight restoration a physician might lead the team, but he or she would need to be "first among equals" as mental health providers and others were added.

At first we focused on inpatient medical stabilization, as the adolescent-medicine physicians at Stanford had done, followed by outpatient follow-up. After a few years the appalling rate of repeat hospitalization forced me to devise a step between the hospital and outpatient follow-up. The first of several intermediary units (Day Treatment Units) was created and expanded upon. These step-down units proved a crucial aid in achieving early and lasting remission in childhood. Later, a unit was added for college-aged young adults, an often-forgotten treatment group. Meanwhile data began to pour in from genetics and the basic sciences about this, and other, brain disorders once thought volitional. Slowly people at international conferences became less opposed to hearing about the biology of eating disorders. I met a handful of Australian adolescent medicine physicians (Michael Kohn and Simon Clarke of the University of Sydney), PhD nutritionist Jenny Odea also from the University of Sydney, and—yes—psychiatrists (Sloane Madden and the late, great Peter Beumont of the University of Sydney) who were determined to bring the world of eating disorders into the twenty-first century. Walter Kaye, formerly of the University of Pittsburgh School of Medicine and currently at U.C. San Diego, and Cynthia Bulik at the University of North Carolina at Chapel Hill have led the research vanguard for the genetic basis of eating disorders in the United States. At the Kartini Clinic we have

begun a collaboration with Dr. Roger Cone and his team to join others in specifically looking for a locus of vulnerability in children.

And then that battered contingency, the parents, began to collaborate in earnest. The more widespread introduction of family-based approaches has helped hold all providers accountable for reviewing older paradigms of etiology and treatment. It is hard to continue to blame the parents when they prove themselves to be the most powerful agents of change on the clinicians' team.

And the patients continue to be our teachers.