Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder

James D. Lock

ROUTLEDGE

"Professor Lock's wealth of clinical experience, wisdom, and skill, is deftly captured in this well-structured, clearly written book. It represents a significant step towards addressing current limitations in evidence-based guidance for clinicians working with families affected by ARFID. The welcome addition of three chapters illustrating the practical application of the material covered, and the emphasis on integrating developmental, physical, and mental health aspects of ARFID presentations in treatment, enhances its accessibility and relevance. A highly recommended volume."

Dr. Rachel Bryant-Waugh, *consultant clinical psychologist, lead clinician ARFID Service*

"This book is a much-needed addition to the clinician's armamentarium for treating children and adolescents with Avoidant/Restrictive Food Intake Disorder (ARFID). Dr. James Lock has eloquently summarized the research literature on the topic of Family-Based Treatment (FBT) for ARFID; subsequently taking the reader through a step-by-step application of this method. For those who are already familiar with FBT, the book clearly describes the differences between FBT for Anorexia Nervosa and Bulimia Nervosa compared to FBT for ARFID. One of the most useful aspects of this manual is a thorough description of ARFID subtypes and how FBT is modified for each. In addition, the developmental aspects of eating behaviour are clearly reviewed and carefully considered in the implementation of this treatment. This is an excellent resource for anyone working with children and adolescents with eating disorders, disordered eating or feeding issues."

Jennifer Couturier, *MD, MSc, FRCPC, FAED, child and adolescent psychiatrist, medical co-director, Eating Disorders Program, McMaster Children's Hospital, associate professor, McMaster University, Ontario, Canada*

"From one of the creators of Family-Based Treatment (FBT)—the leading evidence-based therapy for eating disorders in youth—comes an adaptation of FBT for avoidant/restrictive food intake disorder (ARFID) in young people. This engaging manual is well-written, sensible, and will feel like a familiar yet missing tool for clinicians caring preschoolers, school-age children, and teens with ARFID. Capitalizing on the family as a resource, FBT-ARFID empowers parents to use the skills they already have to help their children eat and thrive."

Jennifer J. Thomas, *PhD,* and **Kamryn T. Eddy**, *PhD, co-directors, Eating Disorders Clinical and Research Program, Massachusetts General Hospital; associate professors of Psychology, Department of Psychiatry, Harvard Medical School; co-authors,* Cognitive-Behavioral Therapy for Avoidant/Restrictive Food Intake Disorder: Children, Adolescents, and Adults

"Demonstrating once again the potential of a well written treatment manual to transform both research and clinical care, Lock and colleagues have poured their clinical experience and scientific knowledge into this synthesis of the Family-Based

Treatment approach to Avoidant/Restrictive Food Intake Disorder (ARFID). The crucial theoretical, developmental and scientific bedrock on which the approach is built is articulated in the opening chapters, delivered with accessible clarity and abounding with clinical experience. The treatment itself is outlined in three chapters, one for each phase, followed in subsequent chapters by detailed case examples addressing adaptations for each of the three main ARFID subtypes, low interest, sensory sensitivity and fear of adverse consequences. For experienced FBT therapists the style and structure will be familiar; the richness comes through the numerous vignettes and therapist dialogue scattered throughout, from which the authors' experience of effectively supporting young people and parents shines through. This will become a standard text for any eating disorders therapist working with children and young people."

Dasha Nicholls, *clinical reader in Child Psychiatry, Imperial College London and past president of the Academy for Eating Disorders*

Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder

This book describes the theoretical and clinical rationale for the use of Family-Based Treatment (FBT) for Avoidant/Restrictive Food Intake Disorder (ARFID).

Based on years of clinical care and systematic study of children and adolescents with ARFID using Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder (FBT-ARFID), the manual provides guidance about assessment of ARFID. Topics covered include how to incorporate the medical, nutritional, and psychiatric problems that are common with this disorder and how to evaluate the principle maintaining behaviors related to lack of interest or appetite, extreme sensory sensitivities to food, and fear of physical repercussions of eating (e.g. pain, vomiting, allergic reactions). Step-by-step illustrations of the key interventions in FBT-ARFID are provided and detailed case discussions demonstrate how these are implemented in a range of cases.

Ideal for clinical practitioners who treat children and adolescents with eating disorders, specifically, psychologists, psychiatrists, social workers, and allied health practitioners.

James D. Lock, MD, PhD, The Eric Rothenberg, MD, Professor of Psychiatry and Pediatrics, Stanford University School of Medicine.

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Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder

James D. Lock

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I dedicate this work to the many professionals, patients, parents, and families who have contributed to developing Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder.

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Contents

Illustrations

Figure

Tables

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List of Acronyms

ABA	Applied Behavioral Analysis
ADHD	Attention Deficit/Hyperactivity Disorder
AFT	Adolescent Focused Therapy
AN	Anorexia Nervosa
ARFID	Avoidant/Restrictive Food Intake Disorder
ASD	Autism Spectrum Disorder
ASN	Always, Sometimes, Never
ASQ	Ages and Stages Questionnaire
BAI	Beck Anxiety Inventory
BDI	Beck Depression Inventory
BED	Binge Eating Disorder
BMI	Body Mass Index
BN	Bulimia Nervosa
CBCL	Child Behavior Checklist
CBRS	Connors Comprehensive Behavior Rating Scale
CBT	cognitive-behavioral therapy
CBT-AT	cognitive-behavioral therapy for ARFID
CDI	Child Depression Inventory
ch-EDE	Eating Disorder Examination (child version)
CIA	Clinical Impairment Assessment
CPSS	Child Post-traumatic Symptom Scale
CRT	cognitive remediation therapy
CY-BOCS	Children's Yale-Brown OC Scale
DSM	Diagnostic and Statistical Manual of Mental Disorders
EDA-5	Eating Disorder Assessment for DSM-5
EDE	Eating Disorder Examination
EDE-Q	Eating Disorder Examination (self-report version)
EDNOS	Eating Disorder Not Otherwise Specified
EDY-Q	Eating Disorders in Youth Questionnaire
EKG	electrocardiogram
EOT	end of treatment
ES	effect size
FAC	fear of adverse consequences

FBT	Family-Based Treatment
FBT-ARFID	Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder
FNS	Food Neophobia Scale
GAD	Generalized Anxiety Disorder
GI	gastrointestinal
IEP	Individualized Education Plan
IPT	Interpersonal Psychotherapy
LOI	lack of interest
MASC	Multidimensional Anxiety Scale for Children
NIAS	Nine Item ARFID Screen
OCD	Obsessive-Compulsive Disorder
ODD	Oppositional Defiant Disorder
ODDRS	Oppositional Defiant Disorder Rating Scale
PARDI	Pica, ARFID, and Rumination Interview
PFT	Parent Focused Therapy
PSC	Pediatric Symptom Checklist
PTSD	Post-Traumatic Stress Disorder
RCT	randomized controlled trial
SCARED	Screen for Anxiety and Related Disorders
SCQ	Social Communication Questionnaire
SDQ	Strengths and Difficulties Questionnaire
SRS	Social Responsiveness Scale
SS	sensory sensitivity
SSRIs	serotonin reupdate inhibitors
SyFT	Systemic Family Therapy
TAU	treatment as usual

Introduction

There are no interventions for Avoidant/Restrictive Food Intake Disorder (ARFID) with a strong systematic evidence base. In fact, the evidence base for the treatment of all eating disorders in children and adolescents is very limited. However what evidence is available suggests family involvement is likely helpful and a specific approach called Family-Based Treatment (FBT) is currently considered the first line treatment for Anorexia Nervosa (AN) and Bulimia Nervosa (BN) in children and adolescents (National Institute for Clinical Excellence 2004, Lock et al. 2015). Recent studies suggest that this approach is feasible and leads to clinical improvements in children with ARFID and it is these findings along with the effectiveness of FBT for AN and BN that this treatment manual is based (Lock et al. 2019).

Family therapy for eating disorders in children and adolescents has long been recommended by clinicians, but systematic support for it lagged behind. Further, a variety of family therapeutic approaches were developed and used clinically, but none systematically tested. The field of family therapy itself was often at odds with itself, divided into factions and schools that were sometimes fractious. Nonetheless, important insights into how to help families struggling to help their children with eating disorders were identified as well as interventions that would prove to be useful to these families. One significant challenge to families themselves who were treated with some of these approaches was the pejorative and pathologizing nature of some of these family treatments. Salvador Minuchin's famous description of psychosomatic families (eating disorders being conceived of as a psychosomatic disorder) characterized by enmeshment, rigidity, overprotectiveness, and lack of conflict resolution is a prime example of this (Minuchin et al. 1978). Learning family therapy was also largely based on a model of discipleship where the therapist learned from a "master" clinician and without the use of manuals or other codifications of therapy to allow for reproducibility, scaling, or testing. In contrast, cognitive-behavioral therapy (CBT) moved quickly to address these limitations through the development of manuals, training protocols, and systematic testing. This in turn has allowed significant progress in developing an evidence base supporting the use of CBT for a range of mental disorders, including eating disorders in adults.

Resistance to manuals by some therapists, particularly those with a theoretical base in relationship-based (therapeutic alliance) and psychodynamic theory is a

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known impediment to adopting manualized treatments (Couturier et al. 2013). They view manuals as "cook books" and see them as facile, inattentive to complexity, insufficiently attentive to patient uniqueness, and lacking respect for professional skill and judgment—among other concerns. This perspective has some merits of course, but on the other side, leaving treatment to be shaped entirely by professional personal opinion is also highly problematic. Not only do patients not know what to expect in terms of intervention and process, they also have no way to compare or assess such approaches in terms of expected outcome. Imagine a surgeon practicing without protocols to guide decision making or an oncologist deciding on her own therapeutic regime based on her professional opinion without reference to scientific data. For a long time this state of affairs for therapists treating eating disorders was tolerated because there were just no manuals to use, no guidance to follow, and few research studies to support specific approaches.

The current manual is the result of many years of clinical care of children and adolescents with ARFID and more recently systematic study of Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder (FBT-ARFID). It aims to both respect skills and judgment of therapists, while also providing a treatment frame, therapeutic style, and specific intervention strategies to guide a reproducible treatment. The beginning of the book focuses on preparing the therapist with the knowledge needed to best use FBT-ARFID and then proceeds to more detailed descriptions of specific interventions and skills followed by detailed case examples.

Chapter 1: What is Avoidant/Restrictive Food Intake Disorder? Chapter 1 describes the clinical presentation of Avoidant/Restrictive Food Intake Disorder (ARFID). This chapter describes the history of these types of eating problems in children and adolescents and presents current data on epidemiology, risk, and treatment.

Chapter 2: An Overview of Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder. Chapter 2 provides a summary of the FBT-ARFID. This chapter reviews the theoretical rationale and underlying model of FBT-ARFID. It describes the similarities and differences of FBT-ARFID from FBT for AN or BN. The three phases that constitute FBT-ARFID are described and the main interventions used are introduced.

Chapter 3: Scientific Support for Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder. This chapter reviews the current evidence base for FBT and FBT-ARFID to inform therapists about what we know about efficacy and effectiveness of this approach. These data should also help therapists to make determinations about whether FBT-ARFID is a reasonable approach to consider in specific cases.

Chapter 4: Challenges in Diagnosis and Assessment of Avoidant/Restrictive Food Intake Disorder. This chapter reviews the procedures necessary to conduct a diagnostic assessment for children and adolescents with possible ARFID. Common challenges, complexities, and developmental issues are discussed as they relate to the initial presentation of ARFID.

Chapter 5: Applying Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder Through a Developmental Lens. ARFID commonly onsets as a disorder in childhood, but it can occur in very young children, teenagers, and adults. Using FBT-ARFID requires an appreciation of normal development because these processes will have an impact on how best to implement it effectively for these different age groups. Specifically, cognitive, emotional, social, and familial changes associated with different stages of development impact how therapists engage families, support learning behavioral changes, and ways to best involve the child.

Chapter 6: Managing Medical and Psychiatric Co-Morbidity in Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder. Children and adolescents with ARFID often have other medical and psychiatric co-morbid problems, including malnutrition, vitamin deficiency, growth retardation on the medical side, and attentional, behavioral, and emotional problems on the psychiatric side. These co-morbid problems pose challenges for families and therapists implementing FBT-ARFID. Strategies about how to prioritize and focus treatment when these types of co-morbidities are present are discussed in this chapter.

Chapter 7: Empowering the Family for Change: Phase 1 of Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder. The first phase of FBT-ARFID is about motivating and empowering parents to make changes in their management of food and eating in their child with ARFID. Session 1 is focused on understanding the impact of ARFID on how the child and family are functioning both at mealtimes and in other interactions at home, school, and other social situations. It also provides an opportunity for the therapist to address parental guilt and self-blame as interfering with behavioral management. The session is also an opportunity to highlight the medical, psychological, developmental, and social difficulties their child will likely face without decisive action. This information is used to emphasize the seriousness of ARFID and to increase motivation for change in the parents. This phase also includes a family meal aimed at helping the therapist learn more about the child, parental, and family behaviors at mealtimes and to provide an opportunity for the therapist to learn more about how well the parents are working together to change mealtime behaviors. The remainder of Phase 1 consists of six–eight sessions aimed at helping the parents becoming increasingly effective in challenging the behaviors that maintain ARFID through ongoing review, consultation, and planning.

Chapter 8: Changing Eating Behaviors in the Family and Social Context: Phase 2 of Family-Based Treatment for Avoidant/Restrictive Food Intake Disorder. This chapter focuses on the second phase of FBT-ARFID. The main aim of this phase is to promote generalization of the changes around mealtimes and eating that have been mastered in the home setting during Phase 1 to the other social and environmental contexts such as school, outings, restaurants, and traveling for more extended periods. During this phase there is growing independence on the part of the child for increased self-management around eating as parents step back.

Chapter 9: Returning to Developmental Norms: Phase 3 of Family-Based Treatment for Avoidant Restrictive Food Intake Disorder. Phase 3 is not necessary for pre-

adolescents because it is primarily aimed at helping adolescents with ARFID step back into the level of independence and self-management expected of teenagers. Because FBT-ARFID requires parental management of mealtime behaviors during the first two phases, this is particularly developmentally out of sync for adolescents compared to younger children. This phase helps adolescents in re-establishing themselves as developing and independent individuals and promotes parental awareness and support of adolescent processes.

Chapter 10: Family-Based Treatment for Low Interest Avoidant/Restrictive Food Intake Disorder (contributed by Nina Kirz, MD). This chapter provides a detailed account of FBT-ARID as applied with a young boy with low interest in eating.

Chapter 11: Family-Based Treatment for Sensory Sensitivity Avoidant/Restrictive Food Intake Disorder (contributed by Danielle Colborn, PhD). This chapter is a detailed account of FBT-ARFID used to treat a patient with sensory sensitivities.

Chapter 12: Family-Based Treatment for Fear of Adverse Consequences Avoidant/Restrictive Food Intake Disorder (contributed by Shiri Sadeh-Sharvit, PhD). This chapter describes how FBT-ARFID was used to treat a patient who developed ARFID as a result of a fear of adverse consequences.

Chapter 13: Where to From Here. This chapter focuses on the need for but challenges associated with training, dissemination, and implementation of FBT-ARFID. It also reviews measures of fidelity to the approach to assist therapists in their learning and mastery of FBT-ARFID.

It should be noted at the outset that this manual is intended to be used by clinically trained and licensed mental health professionals. It is not a self-help manual. The manual assumes basic skills in therapeutic management of children and adolescents, an understanding of child and adolescent development broadly, and experience and comfort working with families. Children and adolescents with ARFID can become medically severely ill and it is expected that therapists treating these children understand this possible eventuality and will have the support of a medical provider (e.g. a pediatrician) when caring for them. Further, many children will have significant psychiatric co-morbidities that may require additional treatment and sometimes psychotropic medication. For these patients, appropriate ancillary care including psychiatric consultation and management is expected to be part of the treatment for ARFID. In other words, treating ARFID often requires a team of professionals working together to achieve the safest and best outcomes.

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1 What is Avoidant/Restrictive Food Intake Disorder?

In this chapter we describe Avoidant/Restrictive Food Intake Disorder (ARFID), the specific diagnostic characteristics, differences between ARFID and other eating disorders, prevalence, etiological theories, risks, common presentations, and common co-morbidities—both medical and psychiatric. The purpose of the chapter is to help therapists using this manual to have a ready reference for understanding ARFID and to consolidate the existing literature for efficient use by practicing clinicians.

Historical Context

The diagnostic category *Avoidant/Restrictive Food Intake Disorder (ARFID)* was first introduced to the Diagnostic and Statistical Manual of Mental Disorders (DSM) in its fifth iteration (DSM-5) in 2013 (American Psychiatric Association 2013). Of course, the clinical problems that are described as constituting this "new" disorder had been present in patients previously, but were variously diagnosed using other diagnostic formulations including Feeding Disorders of Infancy and Early Childhood, Eating Disorder Not Otherwise Specified (EDNOS), Specific Phobias, and various psychosomatic diagnostic categories. None of these diagnostic categories, however, were satisfactory diagnostic homes for the range of eating problems that ultimately has come to be called ARFID. Many with these eating problems were found in infants or young children, and the vagueness of EDNOS failed to capture the specificity of the eating problems and therefore provided little guidance about treatment. In addition, while some patients with ARFID had fears about choking or regurgitation, the conceptualization of the eating problem as a specific phobia was a misnomer. The interplay between psychiatric symptoms and physical health that characterized psychosomatic disorders was a somewhat better fit, but the putative unconscious and psychodynamic underpinnings of this diagnostic category did not align with the usual gradual onset and maintenance of the eating problems for many with ARFID. In sum, then, patients often were diagnosed without much specificity, treated with a range of interventions that were applied without much standardization, treated by a range of professionals often with little mental health training, and in clinics that were not specific to eating problems or disorders (Eddy et al. 2015). Needless to add,

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perhaps, is that this jumble made it largely impossible to study this condition and develop systematic interventions, understand better the risks for the disorder, and identify ways to prevent it. While the elaboration of the diagnosis of ARFID in DSM-5 has done much to improve this situation, there remain significant challenges about the coherence of this diagnostic formulation (Bryant-Waugh and Kreipe 2012).

Current Diagnostic Criteria

According to the DSM-5, to meet diagnostic criteria for ARFID there are four cardinal features:

1 A clinically significant and sustained difficulty with eating for health;
2 No clinically significant body image disturbance or fear of weight gain;
3 Not diagnosed with anorexia or bulimia nervosa; and
4 The feeding and eating problem is not the result of another medical problem.

If these eating behaviors are sustained the health of the child in terms of weight, growth, and nutritional deficiencies can become severely compromised. In some cases, these types of nutritional impacts can be forestalled through the use of nutritional supplements, tube or enteral feeding short term, but when dependency on such measures develop, the diagnosis of ARFID is more likely. Finally, the result of these eating problems must lead to significant psychosocial impairment. While this criterion is subject to clinical interpretation, the intent is to exclude children and adolescents with mild food phobias, dislikes, and struggles over eating with parents and instead require that these problems rise to the level that interfere with actual social, school, and family functioning and are associated with distress and dysfunction.

A cardinal feature of ARFID is the requirement that there be no body image disturbance associated with the eating problem. This is a crucial distinction between ARFID and other eating disorders such as AN and BN. Body image disturbance is defined as an over valuation of weight and shape as a source of self-worth or self-esteem. A person with normative valuation of appearance related to weight and shape could have ARFID. An adolescent who worries about being too fat or too thin within the context of developmental norms that might often be greater than an adult or child could also have ARFID. What constitutes "disturbance" in body image is not precisely defined, but operationally and practically, if the eating behaviors are used to influence or change body weight or shape, there is a high likelihood that there is body image disturbance and ARFID is not the correct diagnosis.

Excluding the presence of a diagnosis of AN or BN is an extension of the criterion excluding body image disturbance. Body image disturbance is a key feature of both of these "classical" eating disorders. Importantly, however, this criterion expands upon body image disturbance because other criteria used to

diagnose AN or BN (and others) also appear to overlap with the criteria to diagnose ARFID. For example, fear of weight gain, a criterion for AN, might be confused with fear of choking or vomiting which are found in some types of ARFID. Similarly, low weight, another key feature of AN, is often found in patients with ARFID, but importantly, low weight in ARFID does not result from attempts to lose weight, but rather a consequence of inadequate nutrition without this purpose. The behaviors of under eating in ARFID may look like dieting, but are not intentional dieting to lose weight. There may be similar medical problems in ARFID patients with low weight as with AN—such as bradycardia (low heart rate), variable or low blood pressure, and low body temperatures—but again, these are the result of malnutrition common to both conditions. Because some ARFID patients may over eat—especially foods they particularly favor—this behavior might sometimes be confused with binge eating in BN or Binge Eating Disorder (BED). However, unlike BN, ARFID patients are not compensating for caloric restriction nor do they feel guilty afterward or try to purge their foods to prevent weight gain. Some ARFID patients may vomit as a response to eating, but again, this is not compensatory nor aimed at preventing weight gain. Instead, vomiting, when it occurs in ARFID, is typically a response to anxiety about choking or another physical reaction (allergic or other medical reaction) rather than to affect weight.

The last criterion for ARFID is the exclusion of a medical condition as the primary cause of the eating disturbance. This does not mean that there can be no medical condition contributing to the eating problem, but rather that the eating problem requires treatment above and beyond the resolution of the medical problem. Indeed, many patients with ARFID are first identified in the context of treatments for medical conditions, especially gastrointestinal (GI) disorders. For example, in a retrospective examination of the source of clinical referrals for ARFID about half of the patients came from a medical clinic (Eddy et al. 2015). This can be a source of confusion for patients, parents, and physicians because the symptoms of ARFID appear related to the GI disorder (and may indeed be in part), so hopes are often pinned on the notion that the eating problem will resolve with the successful treatment of the GI problem. Indeed, many mild to moderate eating disturbances in this context do resolve themselves and do not require separate treatment. However, for those that do not resolve themselves, a diagnosis of ARFID and treatment for the condition is warranted.

Clinical Presentations of ARFID

While there are no systematically or scientifically verified "subtypes" of ARFID, there are three major clinical presentations that are typical: Lack of interest in eating or low appetite; sensory sensitivity or highly selective eating; and fear of adverse consequences of eating such as choking, vomiting, or allergic reactions. While each of these presentations differs in terms of clinical symptoms, all currently fall under the diagnostic category of ARFID. In future, these presentations may be codified as true differing subtypes, or alternatively may be diagnostically

separated. As a relatively recent diagnostic category this kind of ambiguity is to be expected, and still is a major advance over the previous scattered diagnostic categories used for these behaviors before the ARFID diagnosis was introduced. Let's delve a bit deeper into these different presentations to illustrate the range and heterogeneity of ARFID.

Lack of Interest (LOI)

Lack of interest (LOI) or low appetite is a common form of ARFID that often is associated with a long duration, beginning in a number of cases with failure to thrive as an infant. These patients are underweight, though not always markedly so, and usually track in the lower percentiles for height and overall growth. While they may be otherwise progressing well in their development, concerns about low appetite and under eating have usually been long standing for the parents and medical providers. The parents have often tried to promote increased eating, but have not been successful and have "given up" the fight. Children with LOI usually present between the ages of 4–10 and are usually indifferent to any consequence of under eating and do not experience a problem with their eating except for fighting with their parents about it. These children usually eat the full range of foods but only in small quantities. Some may show a preference for fruits and vegetables over proteins and complex carbohydrates, which can also contribute to low weight or poor weight gain. Usually these children do not like to spend time eating or sitting at the table and prefer to talk, play, or otherwise engage themselves. They sometimes forget to eat because of these other interests and when at school they often prefer recess activities to lunch. The parents often find themselves "begging" their child to eat but the child remains blithely unresponsive to this.

> *Alyssa is a bright, energetic 6-year-old whose parents bring her into the clinic for evaluation because the pediatrician is concerned that she is very short and underweight for her age. Her parents report that Alyssa has always been small and thin. Even as an infant she did not suckle readily and she required supplemental bottle feeds. Nonetheless, she developed normally from a motor, behavioral, and cognitive perspective meeting expected milestones, except her weight has always below the tenth percentile. Her parents are of average height and weight and Alyssa's sister, 1.5 years younger, is already heavier and taller than Alyssa. Her parents describe how their efforts to get Alyssa to eat more were unsuccessful. She would sit at the dinner table playing with her food or talking rather than eating. They tried punishing her, but they felt bad about this because she said she couldn't eat because her stomach hurt or she was full.*

Sensory Sensitivity (SS)

Sensory sensitivity (SS) or highly selective eaters are another common presentation of ARFID. These children should not be confused with children who

are simply somewhat choosey or whose palettes are still developing and do not like stronger tasting foods. Instead, these children display extraordinary sensitivity to taste, texture, and sometimes temperature and color of foods. The classic example of such a child is a young boy who will eat only plain pasta, white bread, and cheerios. These bland foods are predictably tolerated because they do not lead to high sensory sensations of any kind. They are easy to chew, look plain, have little taste and little smell. Often these foods also need to be served at close to room temperature if they are to be consumed. In contrast, these children reject any foods that they perceive as increasing sensations—sauce, green vegetables, many meats (because of the texture and smell), and even mildly spiced foods. As with LOI, these predilections are using long standing, often beginning in toddlerhood. Also similar to LOI, parents have often tried to change these eating patterns to no avail because rejection of any unacceptable foods raises anxiety about insufficient nutrition. These children may be underweight, normal weight, or even overweight depending on how much they eat and what their choices are. Many will consume sugary drinks and foods (like boxed cereals) with low nutritional value but with high calories. Sometimes these children have other psychiatric problems, especially related to attention, oppositional behavior, and autism spectrum disorders.

> *Tony is a 9-year-old boy whose parents bring him to the evaluation because they are worried about his nutrition. They say he has always been picky about what he eats, beginning at age 1 or 2. They have tried repeatedly to get Tony to eat, but he refuses. He currently eats a very limited diet that includes white bread, plain pasta, fruit juices without pulp, processed cereal, string cheese, and soft drinks. Tony appears slightly overweight, pale, and has a sullen demeanor. He says his parents constantly "bug" him about eating and he is tired of it. He can't help what tastes good or bad to him, he says, and when they try to make him eat, he gets angry. Tony has seen a therapist in the past for oppositional behavior and attention problems.*

Fear of Adverse Consequences (FAC)

The third typical presentation of ARFID is fear of adverse consequences from eating (FAC). Patients with ARFID who present this way usually report a relatively acute onset of symptoms, lasting weeks of months rather than years, as is often the case with LOI and SS presentations. These children and adolescents are usually older than children with LOI or SS though this is not always the case. In most cases of FAC ARFID there is an identifiable precipitating event that triggered the eating disturbance. Common events include sudden unexpected choking or gagging, vomiting, or allergic reaction to a food that starts off the fear. Children with FAC change their patterns of eating in response to these events by decreasing their intake, changing the foods they will eat, and increasing efforts to avoid anxiety about eating. Decreasing intake is accomplished by simply not

eating meals or snacks for fear that if they do the choking, gagging, or vomiting will recur. Many children and adolescents with FAC ARFID will only eat liquid, pureed, or very soft foods for the same reasons. They expect these foods will be easier to swallow and therefore think they are safe to consume. Fear is the main emotion children with this form of ARFID experience and in this way, they are similar to the fear of eating that children with AN experience. This fear can be extreme and associated with behavioral dysregulation, again not unlike adolescents with AN who are asked to eat. However, this fear is not related to weight gain or appearance, but instead to a fear of choking, gagging, or some other physical reaction to swallowing. Because this form of ARFID is often less chronic, parents are surprised by the eating behavior and the strong emotions associated with it and are often unprepared to help manage or change the eating behavior. They are also often confused and worried about the extreme distress their child is experiencing and as a result are hesitant to intervene decisively, especially when the disorder is just beginning. Thus, unlike parents with children who present with SS or LOI—who are usually highly familiar with the behaviors and have often given up on changing them—these parents are more like the parents of children who develop AN, unprepared and uncertain about how best to proceed. The children and adolescents that develop this form of ARFID may more commonly have anxiety or depressive disorders and, indeed, these other psychiatric disorders may increase risks for FAC ARFID. For a range of reasons, FAC is often the most difficult to distinguish from more typical eating disorders. Because of a change in eating, these patients often lose weight and can become malnourished similar to AN. As noted, their fear also shares an emotional overlap with AN even though it is not related to fear of weight gain. Because they are sometimes older than SS or LOI patients, they are perceived as being more in the adolescent risk group for AN as well. In addition, FAC can sometimes be confused with BN, because vomiting sometimes occurs after eating. This vomiting, however, is not volitional and is not aimed to compensate for eating, but rather an unintentional consequence of eating and anxiety about eating. Other medical conditions may be present with FAC and sometimes the triggering event is a medical procedure (such as an endoscopy). Again, the presence of other medical problems often complicates the picture both from a diagnostic and intervention point of view. As a result, patients and parents are sometimes suspicious of an ARFID diagnosis and instead want to focus on medical or biological explanations for the eating disturbance.

> *Melissa is an 11-year-old who has experienced a 15-pound weight loss over the past several months following a choking incident that occurred when she was eating and experienced a coughing episode while sick with the flu. Since that time, Melissa has been terrified that it would happen again if she ate. As a result, she only drinks clear liquids and broths and sips these very slowly. Melissa appears sad with dark circles under her eyes. She says she is very worried about how thin she is because she feels weak and sometimes gets dizzy when she stands up. Her loving parents have tried to be supportive and not press too hard to make Melissa eat or drink more than she's comfortable with.*

When they have tried to encourage her though, she becomes agitated, tearful, and refuses to drink anything at all. Melissa has been treated for anxiety problems in the past, but appeared to be doing well until the choking incident occurred.

It should be pointed out that these presentations as noted on p. 8 are not systemically derived, but are based on clinical observations of common patterns. That said, there are many ARFID patients who present with features from more than one of these groupings. SS may also have symptoms of LOI and FAC may have or develop SS symptoms. So it is important for clinicians to keep in mind that the behaviors associated with ARFID are often complex, subject to change, and, more typically than not, heterogeneous. At the same time, these groupings, as we shall see, can be helpful to therapists in organizing and planning FBT-ARFID.

Epidemiology of ARFID

It is probably not surprising that our understanding of the incidence and prevalence of ARFID is still nascent given the relative newness of the diagnostic category. Nonetheless, some data suggest that general feeding and eating difficulties are fairly common in children, with some reporting that up to a quarter of children experience such problems during childhood (Micali et al. 2011), but most of this resolves on its own without treatment (Mascola et al. 2010). For school-age children (8–13 years of age), a population-based survey conducted in schools in Switzerland identified a point-prevalence rate of 3.2% using a self-report measure that included symptoms consistent with diagnostic criteria for ARFID (Kurz et al. 2016). An Australian study of older adolescents and adults found a three-month point-prevalence rate for ARFID in the general population of 0.3% (Hay et al. 2017). In both these studies, males and females were equally likely to report ARFID.

In general, studies in medical clinics report higher prevalence rates than community samples, ranging from 5–15% (Norris et al. 2012, Fisher et al. 2014). Even higher prevalence rates were identified in eating disorder programs (9–23%) (Nicely et al. 2014).

Risks and Etiology

Risks for the development of ARFID are under investigation. There are likely genetic contributions for risk related to taste sensitivities and preferences (Breen et al. 2006), anxious temperaments, and autistic traits. Childhood picky eating may contribute to the risk for an eating disorder, including what is not called ARFID (Marchi and Cohen 1990). Although unclear if avoidance of new foods (food neophobia) is environmentally modeled, genetically informed, or both, children whose parents with greater food neophobia have children who are also food neophobic (Dovey et al. 2008). Children with GI problems are commonly referred for ARFID treatment and, thus, these problems may