

Cognitive-Behavioral Therapy for Avoidant/Restrictive Food Intake Disorder

This practical, accessible manual, written by two of the leading experts in the emerging ARFID field, will be a very welcome addition to the clinician's library. I anticipate that it will quickly become a much used volume by anyone offering care and treatment to patients with this disorder. Until now there has been very little by way of guidance in terms of evidence-based treatments specifically for ARFID. This clearly written book, based on sound theoretical principles, enables the outstanding skills, expertise, and insights of its authors to be shared by a much wider audience, which can only benefit patient care.

Dr. Rachel Bryant-Waugh

It is rare that a newly conceptualized mental disorder is introduced into systems of nosology without an existing treatment approach with some evidence for efficacy; but, this was the case with ARFID. Now, from one of the leading eating disorders centers in the world comes a very well-conceived stage model of intervention that can be personalized for the individual patient, as well as the patient's family. Anyone treating eating disorders should find this new clinical manual invaluable.

Dr. David H. Barlow

ARFID sounds a little less unfamiliar today than when it was introduced by DSM-5 only five years ago. Since then, a small cadre of clinical researchers has devoted considerable energy to explore treatments for this patient population. Thomas and Eddy have been leaders in this domain. Through their focused efforts, the authors have put together an extraordinarily helpful treatment manual that everyone who wants to learn more about ARFID, whether a treating clinician, curious trainee, or worried parent, would be well advised to consult. This clinician manual first provides the reader with an excellent psycho-educational overview of ARFID, before delineating the four stages of CBT-AR. The authors round out this manual by demonstrating their treatment approach by way of five elucidating clinical case examples. This book is a most welcome addition to the small family of clinical treatment manuals for eating disorders.

Dr. Daniel Le Grange

As an ARFID advocate, author on the topic, and mother to a recovered child with ARFID, I couldn't be more thrilled with this book. Cognitive-Behavioral Therapy for Avoidant/Restrictive Food Intake Disorder is vital toward the education and treatment of ARFID. With comprehensive and detailed information, workable steps for treatment, and actual case studies, this book is desperately needed in the eating disorder community, and one that I wish had been available when our family was struggling to find answers.

For so many years, our daughter was misdiagnosed, misunderstood, and misheard until she received the proper treatment – and that treatment very much mirrors what authors/doctors Jennifer Thomas and Kamryn Eddy outline in their book. It was extremely encouraging to read about CBT-AR and to have so many of the techniques and stages feel familiar to what we experienced with our daughter's treatment.

There is much to learn about ARFID, but this manual is a terrific starting point in helping clinicians, physicians, therapists, and even parents learn more about this very prevalent and very mysterious eating disorder that affects children and adults of all ages.

I can't wait for this book to be published because I am going to single-handedly contact everyone I know who has struggled with ARFID and tell them they absolutely need this manual!

Stephanie Elliot, author of the young adult novel, *Sad Perfect*, ARFID advocate, and mother to a daughter recovered from ARFID

Cognitive-Behavioral Therapy for Avoidant/Restrictive Food Intake Disorder

Children, Adolescents, and Adults

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up-to-date information that is in accord with accepted standards and practice
at the time of publication. Although case histories are drawn from actual
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For Asher and Colby

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Foreword

This book starts with a very simple premise: If you give people a diagnostic label, it helps them identify that they or their loved ones have a legitimate problem, and they feel justified in seeking help. However, then you hit a quandary. You need a way of helping those people deal with that problem when there has not been time to come up with solutions. So, when Avoidant/restrictive food intake disorder (ARFID) was launched onto the world stage in 2013, it was great to have a label, but we had to face individuals with ARFID and their families with the news that we were not ready with any evidence-based treatment. All that we could offer were best guesses, and they were often far from adequate.

The cognitive-behavioral therapy for eating disorders (CBT-ED) approach that works well with many adults with eating disorders has not proven suitable for this group. However, now we have a well-thought-out treatment approach that can bring real hope to those with ARFID, whatever their age. The authors have given us a form of CBT that is adapted for ARFID – for Avoidant/Restrictive Food Intake Disorder (CBT-AR). In this book, it is made clear how CBT-AR differs from CBT-ED, as well as how they overlap.

This book is a true trailblazer, with its combination of clinical knowledge, sound theoretical reasoning, empirical support, and plenty of case material. It is no exaggeration to say that only this team could have produced such an excellent clinical protocol at this time. They have worked at multiple levels to understand ARFID, and have used that research and clinical evidence to develop the therapy that you are going to read about here.

What Jennifer Thomas and Kamryn Eddy have done here (along with their redoubtable team) is to find ways of doing this work with the person with ARFID or their family, according to what is most likely to fit the individual case. Their CBT-AR protocol is soundly based on cognitive-behavioral

principles, which have been honed and refined. In your hands, you have: a staged model that is adaptable to the nature of the individual case; clearly laid out psychoeducational materials; and a manual for parents that will help them get involved as active agents in the treatment process. The stages of therapy and the tasks within each stage are clear to the reader. The penultimate chapter gives vivid case material, showing the thinking that we need to do as we deliver CBT-AR. Anyone who has trouble in understanding how to make CBT-AR work in routine practice can learn from these excellent case examples.

The authors are very clear: The work of our field to understand and treat ARFID is not yet complete, and will be the subject of research and clinical innovation for decades to come. However, this book is the most significant step to date – a bringing together of research and clinical knowledge in order to provide clinicians with the knowledge and skills that they need to be able to work with this challenging clinical population. So now, when a parent or person with ARFID says, ‘I have been given this diagnosis, so what can you do about it?’, we will have an answer and the tools that we need. We should be delighted, and I believe that you will be by the time you have read what follows in this manual and tried it with your patients.

This manual is written to be immediately accessible. It is certainly not going to spend much time on my shelves. It will be where it belongs – on my desk, and getting used. This manual deserves to be on the desks of all clinicians who work with such eating and feeding problems. Jennifer Thomas, Kamryn Eddy, and their team are a formidable group of clinical researchers. This book demonstrates not only their skills but also their dedication to the care of their patients and families.

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Preface

Avoidant/restrictive food intake disorder (ARFID) was introduced to the psychiatric nomenclature in 2013, with the publication of the *Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5)* (American Psychiatric Association, 2013). By naming and describing a syndrome that reflected the symptoms with which many patients and families had long been struggling, the American Psychiatric Association inspired a groundswell of hope for individuals with avoidant and restrictive eating and their loved ones. Indeed, naming a diagnosis implies that the condition may be treatable – that there may be a cure. Over the past five years, hopeful patients and their families have inundated clinics worldwide seeking help for avoidant and restrictive eating. Many of them have come to our own center, the Massachusetts General Hospital Eating Disorders Clinical and Research Program in Boston.

Unfortunately, in 2013, we as a field knew very little about the phenomenology and treatment of ARFID. Although there was already a robust literature

on pediatric feeding disorders and classical eating disorders, ARFID itself was so new that there was no clear standard of care. That is, no psychological treatment had demonstrated clear efficacy in a randomized controlled trial. This created a conundrum for practicing clinicians: What were we to offer the hundreds of patients and families who, heartened by a new diagnosis, honored us with their trust by asking for help? This book describes a specialized form of cognitive behavioral therapy – CBT-AR – that we have developed, refined, and studied in response to this urgent clinical need. CBT-AR is designed for the treatment of children, adolescents, and adults ages ten and up who meet *DSM-5* criteria for ARFID (American Psychiatric Association, 2013) or exhibit clinically significant symptoms of avoidant or restrictive eating. While there is still much to be learned about the etiology, neurobiology, prevention, and treatment of ARFID, patients and their families need help now. It is for this reason that we wrote this book.

Acknowledgments

Developing this treatment was truly a team effort. We would like to thank all of our clinical colleagues, research collaborators, funders, and patients who helped us to better understand the specific psychopathology of ARFID and identify potentially successful interventions. Specifically, very special recognition goes to Dr. Kendra Becker, who served as a study therapist in the initial pilot trial of CBT-AR, provided invaluable feedback that helped us refine the treatment, and assisted in creating the patient education handouts included in this book. We are extremely grateful to our team dietitian, Laurie Manzo RD, for compiling the ‘Common Nutrition Deficiencies Associated with ARFID’ patient education handout based on her clinical experience with this group. We owe a debt of gratitude to all of the members of the Eating Disorders Clinical and Research Program (EDCRP) clinical and research team, who provided important feedback on earlier versions of this treatment, including Drs. Rachel Liebman, Lazaro Zayas, Audrey Tolman, Judy Craver, Cathryn Freid, and Debra Franko. We would also like to thank our current and former EDCRP research assistants, Kathryn Coniglio, Helen Murray, and Ani Keshishian, who helped us with many grant proposals and institutional review board submissions to support this project. This manual would not have been possible without our research collaborators – particularly those on our National Institute of Health-funded study ‘Neurobiological and Behavioral Risk Mechanisms of Youth Avoidant/Restrictive Eating Trajectories’ (1R01MH108595) – including Drs. Elizabeth Lawson and Nadia Micali (the study’s co-principal investigators) and co-investigators Drs. Madhusmita Misra,

Thilo Deckersbach, Franziska Plessow, Melissa Freizinger, Elana Bern, and Lydia Shrier. Special thanks go to our study nurse practitioners, Elisa Asanza and Meghan Slattery, and our study coordinators – Reitumetse Pulumo, Olivia Wons, Christopher Mancuso, Alyssa Izquierdo, and Jenny Jo – for their tireless work on the neurobiology study. We would also like to thank Dr. Sabine Wilhem, who provided invaluable consultation on treatment development and helped us design our CBT-AR pilot study. As we state in the text, it is important to collaborate with physicians who can provide monitoring to this patient group. As such, we wish to thank the physician colleagues who provided medical care for our patients with ARFID, including Drs. Mark Goldstein, Kathryn Brigham, Diana Lemly, Nupur Gupta, Jennifer Rosenblum, and Melinda Mesmer. We also wish to thank Drs. Rachel Bryant-Waugh, Lucy Cooke, and Nadia Micali for working with us on the development of the Pica, ARFID, and Rumination Disorder Interview, which clarified our understanding of the psychopathology of ARFID and its clinical heterogeneity. We are sincerely grateful to the American Psychological Foundation, Hilda and Preston Davis Foundation, and Global Foundation for Eating Disorders, which funded our CBT-AR pilot study; and the National Institute of Mental Health and Harvard University’s Mind, Brain, and Behavior Initiative, which funded our investigation into the neurobiology of ARFID. Last and most important, we are grateful to all of our patients with ARFID and their parents. Each of them had the selflessness to undergo a new, experimental treatment and the vision to see how their study participation could ultimately improve the lives of others.