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POCKET GUIDE TO

Eating Disorders

THIRD EDITION

Jessica Setnick
MS, RD, CEDS-C

Academy of Nutrition and Dietetics
Chicago, IL

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Academy of Nutrition and Dietetics
120 S. Riverside Plaza, Suite 2190
Chicago, IL 60606

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Frequently Used Terms and Abbreviations

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ACT	acceptance and commitment therapy
ADHD	attention-deficit with hyperactivity disorder
AN	anorexia nervosa
APA	American Psychiatric Association
ARFID	avoidant-restrictive food intake disorder
BED	binge-eating disorder
BN	bulimia nervosa
CBT	cognitive behavioral therapy
CFS	chronic fatigue syndrome
DBT	dialectical behavior therapy
DEB	Dysfunctional Eating Behavior Model
DEXA/DXA	dual energy x-ray absorptiometry scan
DSM-5-TR	*Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition—Text Revision
ED	eating disorder
EFFT	emotion focused family therapy
EKG/ECG	electrocardiogram

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EMDR	eye movement desensitization and reprocessing
FBT	family-based treatment
FDA	US Food and Drug Administration
ICD-10-CM	*International Classification of Diseases*, 10th Revision, Clinical Modification
IFEDD	International Federation of Eating Disorder Dietitians
IFS	internal family systems
MHPAEA	Mental Health Parity and Addiction Equity Act of 2008
MI	motivational interviewing
MNT	medical nutrition therapy
NCP	Nutrition Care Process
NES	night eating syndrome
NFPE	nutrition focused physical examination
OCD	obsessive-compulsive disorder
ON	orthorexia nervosa
ONS	oral nutrition supplements
OSFED	other specified feeding and eating disorders
PCOS	polycystic ovary syndrome
PD	purging disorder
PES	problem, etiology, signs/symptoms
PN	parenteral nutrition
PTSD	post-traumatic stress disorder
RD	rumination disorder
RDN	registered dietitian nutritionist
REDs	relative energy deficiency in sport
SE	somatic experiencing
WHO	World Health Organization

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Reviewers

Quinn Haisley, MS, RD
Owner and registered dietitian, Practice Eros Nutrition
Astoria, NY

Kimmie Singh, MS, RD, CDN
Registered dietitian, Body Honor Nutrition
New York, NY

Brianna Theus, RD
Registered dietitian, The Celestial Life
Shelton, CT

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Preface and Acknowledgements

Welcome to the third edition of the *Academy of Nutrition and Dietetics Pocket Guide to Eating Disorders*. My goal with the first two editions was to equip dietitians with concise, accessible, and evidence-based information to guide practice and improve outcomes for individuals with eating disorders. With this edition I added a new goal: to create a fully inclusive depiction of eating disorders that finally lays to rest any stereotypical images of individuals who are at risk. I am grateful to the reviewers, (Brianna Theus, RD; Quinn Haisley, MS, RD; and Kimmie Singh, MS, RD, CDN) for helping me meet that challenge.

This book would never have made it into your hands without my amazingly patient and dedicated editor Stacey Zettle, MS, RDN; Betsy Hornick, MS, RDN; and everyone on the Academy of Nutrition and Dietetics production team working behind the scenes. We all hope this new edition of Pocket Guide to Eating Disorders will serve as a valuable resource in your work.

Finally, allow me to thank you for all you're doing to ensure a better future for your patients. Your dedication to supporting individuals through their recovery is the reason this book exists.

With gratitude,

Jessica Setnick

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About the Author

Jessica Setnick, MS, RD, CEDS-C, is known to dietitians worldwide as an expert in eating disorder nutrition counseling. For the past 26 years, she has worked in every level of eating disorder care and education as a dietitian, speaker, and consultant. Her signature training workshop for health professionals, Eating Disorders Boot Camp, has been attended by thousands of dietitians and other professionals since 2003. She is the author of *The Academy of Nutrition and Dietetics Pocket Guide to Eating Disorders* and several other books.

In 2012, Jessica founded the International Federation of Eating Disorder Dietitians (IFEDD), which has grown to nearly 1,000 members worldwide. Through IFEDD and the Access to Care Project, Jessica advocates for better access to care for individuals with eating disorders and for ending insurance company discrimination and harmful stereotypes.

In 2019, Jessica shared insights into her decades of public speaking experience in *A Dietitian's Guide to Professional Speaking: Expert Advice for Pitching, Presenting & Getting Paid!*, and most recently starting touring the country again with her workshop Healing Your Inner Eater. Jessica's passion is supporting fellow dietitians, so after decades of advising other RDNs, she put all of the most common questions into *The Sleepless Dietitian's Guide: Advice for the Angst that Keeps You Up at Night*. She envisions a world where no one is ashamed to talk about their eating issues and anyone who wants help can get it. Contact Jessica at Jessica@UnderstandingNutrition.com or visit www.JessicaSetnick.com.

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CHAPTER 1

Eating Disorders and the Dietitian

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"How innocent we were when we thought working with eating disorders was a choice."

–Sherry Tarleton, RDN, CNSC

Introduction

Every registered dietitian nutritionist (RDN) needs a working knowledge of eating disorders. It doesn't matter if eating disorders are not your specific practice area; you will encounter individuals with dysfunctional eating behaviors anywhere you work with other humans. Eating disorders are a part of every general and specialty nutrition practice, population, and group because they can affect anyone who eats. And for the most part, the effects are negative. Although sometimes initiated because they seem helpful, when pursued to extremes, eating disorders can cause disease, disability, death, and incredible physical and mental suffering.

Contrary to how it may appear at first glance, the eating disorder field is a work in progress. Causes of eating disorders are still largely unknown. Research on methods of treatment is in its infancy and riddled with controversies. There is no one agreed-upon treatment and no consensus

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definition of recovery. Topics such as end-of-life care, family participation, and whether eating disorders can be cured are still open to debate.

RDNs who specialize in eating disorders have for the most part remained above the fray by focusing on patient-centered, individualized medical nutrition therapy using the Nutrition Care Process. We adapt what we offer to each person, knowing that each of them—and their nutrition—will continue to change throughout their life. We follow the ethical standards of our profession: autonomy, beneficence, and justice.[1] This is nonnegotiable and does not rely on a person having been diagnosed with an eating disorder or even being willing to accept such a diagnosis.

The RDN stance is simple: all individuals experiencing eating disorders deserve access to compassionate assessment, recommendations for rehabilitative nutrition, and assistance with implementation. Our ultimate goals reflect our hope for each person to reach their full potential, even as we accept that these goals are not always attainable. They include:

- Medical, psychological, and physical safety and health, free from weight bias
- Adequate nourishment, with dignity and without fear
- Enjoyable and safe movement, whether independently or in a community, in accordance with ability and preference
- Autonomy to experience or refrain from new foods and freedom from food guilt
- Body respect, from themselves and others, including comfortable clothes and accommodations, and respect for gender identity

And even as we hope for these outcomes, we acknowledge the roles of systemic injustices and historic inequities that no amount of individual responsibility can overcome.

According to a comprehensive report published in 2020, 21 million US residents currently have eating disorders and, based on current patterns, 7.8 million more will develop an eating disorder in their lifetimes.[2] There is a shocking lack of awareness among public health, medical, and even mental health advocacy organizations about how prevalent eating disorders are, leading to indefensible disparities in research and research funds compared with other conditions.[3] Only a small fraction

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of individuals with eating disorders are ever diagnosed, and an even smaller number enter, much less complete, specialty treatment.[4-6] Even deaths from eating disorders are likely under-reported, as they are often attributed to suicide or heart failure, and the US Centers for Disease Control and Prevention do not track eating disorders as a cause of death.

The most significant driver of these problems is a gross misunderstanding of this basic fact: *anyone who eats can have an eating disorder.* Public perception, health care providers, and even eating disorder researchers remain mistaken about who develops eating disorders, what "counts" as an eating disorder, and how a person with an eating disorder looks. These biases are woven into the fabric of eating disorder treatment because of its basis in academic research during a period when anorexia nervosa was the only identified eating disorder and was believed to only affect females. Treatment strategies, recovery rates, and even diagnostic criteria were all based on the "SWAG" stereotype—shorthand for skinny, white, affluent (or adolescent) girl, even though most people with eating disorders do not meet that description.

Thankfully, finally, belatedly, research on eating disorder prevalence in the real world, among all types of people, has begun to be published, bringing awareness to what RDNs in the field have known all along—eating disorders do not discriminate. Individuals with eating disorders are at least as likely to identify as Black, Indigenous, Asian, Latine, or biracial and to be fat, transgender, poor, elderly, pregnant, in foster care, incarcerated, serving or previously having served in the military, on Medicaid, or more than one of these.[5-16] But because these groups have been historically excluded from eating disorder research and care, their members are less likely to be diagnosed with eating disorders, and therefore very unlikely to get specialty eating disorder care.

Moving forward, better education for medical and mental health professionals, more widespread information for the public, targeted research, and a wider variety of treatment options for eating disorders are needed. This will ensure that a) no eating disorder is missed due to ignorance, b) everyone who wants care for their eating disorder can access it, and c) that eating disorder care is beneficial and not stigmatizing, uninformed, or harmful.

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The Dietitian's Role

Because we are skillful observers of the diverse range of human eating behaviors, RDNs are often the first to notice eating-related problems, whether among patients, students, colleagues, family members, or friends. Many of us were motivated to pursue nutrition as a career because of past experiences with our own or a loved one's eating disorder.[17-19] But the general dietetics education path rarely provides adequate skills to address the issues we find in practice.[20-23] Some forward-thinking educators and internship directors include eating disorders in their curricula beyond the very limited requirements, but the majority of RDNs are left to our own devices to find the information we need. In the years when the Academy of Nutrition and Dietetics Food & Nutrition Conference & Expo includes eating disorder topics, these sessions are very well attended. Other times, eating disorders seem to be excluded from the larger conversation about nutrition and dietetics.

RDNs may be the first to identify problematic eating behaviors simply because we're looking deeply into each patient's nutrition. Once educated beyond the stereotypes, RDNs can be open to the many faces of eating disorders and the many ways they hide. We ask the questions no one else has asked, and we're excellent at sifting through information to find the facts, as well as what may remain unspoken. We can be good listeners who don't pass judgement or shame people for their eating behaviors. This allows our patients to share things they have never confided in anyone else. We offer building blocks for nutritional rehabilitation for individuals and education for the community. We raise awareness of the factors known to cause eating disorders and of their early warning symptoms. When given the opportunity, we can identify eating disorders at their earliest stages and ultimately we can change the course of lives.

Box 1.1 lists some of the many functions an RDN may play in the treatment of eating disorders. Box 1.2 on page 7 lists the outcomes of RDN nutrition counseling from the patient's point of view.

In addition to our important roles identifying and promoting healing from eating disorders, RDNs are leaders in the wider eating disorder field.[20,24,25] We lead clinical teams, we lead community organizations, and

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BOX 1.1 Sample Roles of a Dietitian in the Treatment of Eating Disorders

Evaluate the patient's current eating patterns and identify their stated needs and goals.

Share findings and recommendations with the patient and other members of the medical and mental health teams.

Explain the role of nutrition and eating in physical and mental well-being and provide education to challenge inaccurate beliefs about food, while considering social determinants of health and respecting personal and cultural preferences.

Help the patient determine how to implement needed nutritional recommendations within the context of their abilities, level of family or community support, access to food, cultural heritage and experiences, and address difficulties with implementation.

Help the patient create an action plan with agreed upon steps to repair nutritional deficiencies and work toward their goals. Follow up on action plans and modify as more information is received.

Identify nutrition knowledge and skill deficits. Assist the patient in gaining needed information and skills.

Offer active learning activities when appropriate, such as cooking, eating, online or in-person grocery shopping, to help teach new behaviors and acceptance of food-related tasks and environments. Model appropriate eating in shared experiential interventions such as restaurant meals.

Educate about the harms of detrimental comments and beliefs around food, eating, and body size. Identify which of these may respond to intervention vs those which are not within the patient's control. Address these when within the registered dietitian's scope of practice and refer to other providers as needed.

Assist the patient in recognizing the impact of weight stigma, diet culture, and social determinants of health in their life and present options for managing them (when possible) in medical, social, and other settings.

Include other members of the interdisciplinary treatment team, family members, significant others, support partners, etc., in sessions as appropriate; educate regarding eating disorders and nutrition as they relate to the patient's treatment plan and recovery needs.

Refer to additional care as needed, including specialty medical care, psychiatry, mental health care, and other treatment levels.

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BOX 1.1 Sample Roles of a Dietitian in the Treatment of Eating Disorders (cont.)

Teach group nutrition classes to patients, their families, and support partners, and lead group nutrition discussions that allow participants to express their thoughts and feelings, provide and receive support, address their experiences of diet culture and dysfunctional eating, and promote improved nutrition.

Document, publish, and share experiences, research findings, and outcomes to advance the field.

we lead by example. RDNs working in this area bridge medical and mental health, develop treatment programs and protocols, educate, counsel, supervise, and convey crucial information to other disciplines.[24] Considering that fewer than one in 10 medical residencies require an eating disorder rotation,[26] the RDN often has the most eating disorder expertise among a patient's health care providers.

RDNs contribute to advances in eating disorder treatment at every level of care.[21,24,25] We've practiced strategies such as harm avoidance, weight inclusivity, and family involvement long before they had names or became buzzwords in the field. Eating disorder professional organizations and advocacy groups with position statements all recognize medical nutrition therapy from an RDN to be a standard pillar of eating disorder care. Why then do some eating disorder treatment methodologies or professionals overlook the RDN's role in eating disorder treatment? Because they limit their search to scientific journals in their own field. Although RDNs have written hundreds of books and articles about our work, these are essentially invisible to researchers from other professions who rely only on what is published in peer-reviewed journals. Combined with the common practice of folding an RDN's contribution to patient care into the general umbrella of "treatment as usual," the relative scarcity of RDNs publishing about eating disorders in peer-reviewed journals is a major barrier to recognition of our role.

A significant roadblock to publishing in journals is that these types of publications require that all research must be approved in advance by an Institutional Review Board (IRB). For decades, only RDNs affiliated

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BOX 1.2 Sample Outcomes of Dietitian-Led Nutrition Counseling

Improved ability to obtain and prepare food
Improved eating frequency or timing
Improved ability to plan for eating opportunities
Improved food, energy, and nutrient intake
Increased variety of foods
Increased comfort with trying unfamiliar foods
Increased comfort with social eating opportunities
Decreased preoccupation with food
Decreased compensatory behaviors after eating
Decreased shame about eating
Decreased loss-of-control eating episodes
Increased comfort or better boundaries around food and eating-related topics and questions
Improved understanding and acceptance of feelings about food
Improved ability to separate food and feelings and manage both appropriately
Improved ability to detect and follow internal hunger and satiety cues
Improved understanding of body weight and size changes over time
Improved understanding of body image and influences on body image
Increased understanding of weight stigma and tools to use when encountering it
Decreased punitive or excessive weight or body checking
Improved understanding of the process of eating disorder recovery

Adapted with permission from reference 20: Setnick J. Interventions used in nutrition counseling for eating disorder treatment: survey results. *SCAN's Pulse*. 2012;31(3).

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with a large institution such as a hospital or university had access to an IRB. This roadblock was removed in 2023, when the International Federation of Eating Disorder Dietitians (IFEDD) established an IRB for use by RDNs. Increased published research on what RDNs contribute to the eating disorder field is crucial to increasing insurance coverage, research funding, and understanding of our essential role.

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Future RDN training should include more awareness of eating disorders and prepare us to take leadership roles in the wider eating disorder field, in eating disorder research, and in eating disorder treatment settings. Our field must also welcome—and recruit!—many more dietitians who are Black, Indigenous, Asian, Pacific Islander, Latine, multiracial, fat, gender diverse, first-generation American, disabled, neurodivergent, and every other identity that our patients share. Eating disorder treatment can and will be better when more voices and experiences are included.

Am I Ready?

Every RDN has something to offer an individual experiencing an eating disorder. The primary requirements are authentic curiosity, respect for autonomy, and willingness to seek guidance from a more experienced RDN when needed. As a specialty practice area, working with individuals experiencing eating disorders can be intense and draining, and to be most effective, requires additional training beyond what is provided in school and internship programs.[21,24,27,28]

If you're new to eating disorder care, do not try to go it alone. Reach out to your supervisor, mental health professionals at your workplace, a networking group for eating disorder professionals such as IFEDD, or a more experienced RDN for guidance. Consider asking your workplace to pay for consultation sessions with an eating disorder specialist dietitian (often referred to as "professional supervision") for assistance with the personal aspects of working in eating disorder care as well as case consultation. When selecting continuing education, focus on eating disorders as well as counseling and mental health topics. (Refer to Appendix E for recommendations.)

If you find yourself doubting your patient care decisions or thinking about work after hours, know that these are common reactions, not signs that you are making mistakes. Try not to feel embarrassed if you don't know something. The eating disorders field is filled with controversies and unanswered questions, and even experts do not have all the answers. Your best assets are curiosity and a willingness to reach out for support.

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If you realize you're not interested in the field, you're not sympathetic toward individuals with eating disorders, or you're easily frustrated with slow or little progress, you may choose a different area of practice. When you encounter an individual with an eating disorder, as you occasionally will regardless of your specialty, speak with your supervisor for guidance and refer the individual to a different RDN if possible.

Even with an affinity for eating disorder treatment, you will encounter individuals whose needs exceed what you can provide. When you feel overwhelmed, get support from your own mental health provider or therapist, your professional supervisor/consultant, or peers. Finally, but importantly, if you're experiencing an eating disorder or you notice unhealthy thoughts or behaviors after a long day of helping others with eating disorders, know that this does not disqualify you from work as an RDN. You do need to seek help, and you may choose not to work with this patient population for a period of time. To be able to care for both your patients and yourself, you need awareness of your own thoughts, stressors, and behaviors as well as active engagement in your own recovery. This assures that when you're with patients, you can meet their needs without disregarding your own, and you can keep your own eating issues separate from the needs of your patients. A meeting with an experienced mental health professional or RDN is a starting place to assess your own relationship with food and determine how to proceed.

The Nutrition Care Process

This book is intended to prepare you for when you encounter an individual with an eating disorder in your professional life. The Nutrition Care Process format is followed throughout the remaining chapters. The Nutrition Care Process is comprised of four steps (assessment, diagnosis, intervention, and monitoring/evaluation) and is outlined in detail in Appendix A.

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A Note on Terminology Used Throughout This Book

The following list details specific terminology used throughout the remainder of this book.

- "Dysfunctional eating behaviors" is used as an umbrella term for all eating and food-related activities that detract from an individual's nutritional health, regardless of the presence or absence of a formal eating disorder diagnosis
- "Patient" is used as a general term for someone experiencing an eating disorder and is interchangeable with "client" or "individual."
- "Support partners" is used to denote the wide range of individuals who may be participating in an individual's care, including caregivers, family members, parents, foster parents, siblings, spouses, significant others, children, legal guardians, home health care workers, family of choice, and others.
- "Supervisor" is used to describe a more experienced professional that an RDN can consult with about challenging situations, and can be someone such as a workplace supervisor, a paid consultant, or mentor.
- "Remote health care delivery" is used to describe phone, video, or online consultations and monitoring and is synonymous with "virtual health care" and "telemedicine."
- "Fat" is used as a neutral descriptor of body size as used by the fat-activist community.

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