


Restrictive Eating Disorders: A Primer

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Disclosures

- I have the following commercial relationship(s) to disclose:
 - § Routledge, publication author, NIH, research funding

Overview



- 1. Describe how eating disorders are brain-based illnesses, not choices
- 2. Identify assessment strategies for effective and timely recognition of eating disorders.
- 3. Describe intervention strategies to engage and support patients/ families across stages of eating disorder treatment.
- 4. Recognize need for team-based care for eating disorders.

Fact or Myth?

- Eating disorders are complex, life-threatening conditions
- Recovery from an eating disorder is possible
- Eating disorders are primarily about food
- Eating disorders are a choice – and for some people, they're a lifestyle.
- The United States has a weight "identity crisis"
- Anorexia is the 3rd most common chronic illness among adolescents in the US (behind asthma and diabetes)
- Families cause eating disorders
- Getting better is just a question of eating
- No one is to blame for an eating disorder

Fact or Myth?

- Eating disorders are complex, life-threatening conditions **FACT**
- Recovery from an eating disorder is possible **FACT**
- Eating disorders are primarily about food **MYTH**
- Eating disorders are a choice – and for some people, they're a lifestyle. **MYTH**
- The United States has a weight "identity crisis" **FACT**
- Anorexia is the 3rd most common chronic illness among adolescents in the US (behind asthma and diabetes) **FACT**
- Families cause eating disorders **MYTH**
- Getting better is just a question of eating **MYTH**
- No one is to blame for an eating disorder **FACT**

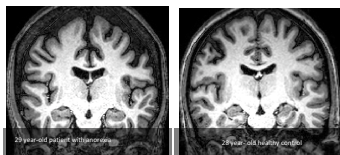
Experiential...
Non-Dominant Hand Activity

- Write, "I am writing with my non-dominant hand."
- Now write, "I feel _____ (insert emotion) while trying to write with my nondominant hand."
- "If you were told that you would need to write with your non-dominant hand the rest of your life, what you would do?" (with non-dominant hand.)

The brain of a person with an eating disorder **fires differently** compared to a person without an eating disorder.

- The "dominant" way for a person **with anorexia nervosa** to respond to food is to:
 - 1. Not eat.
 - 2. Move and keep moving.
- The "dominant" way for a person **with bulimia nervosa** to respond to food is to:
 - 1. Delay eating food as long as possible.
 - 2. Have no control overeating, especially when alone or depressed, without natural sensations, hunger or fullness to regulate when to begin or stop eating.
 - 3. Impulsively purge by vomiting or laxative abuse, etc.
- The "dominant" way for a person **without an eating disorder** to respond to food is to:
 - 1. Eat mindfully when hungry and stop when full.
 - 2. Enjoy the taste.
 - 3. Feel the sense of hunger or fullness.

What is wrong with the brain when someone has an ED?



Translation to Function




- Cognitive integration
 - lost in details, "not getting the big picture"
- Impaired decision making
- Diminished social cognition
- Mood disturbance
- Difficulties with executive functioning
 - Academic, occupational

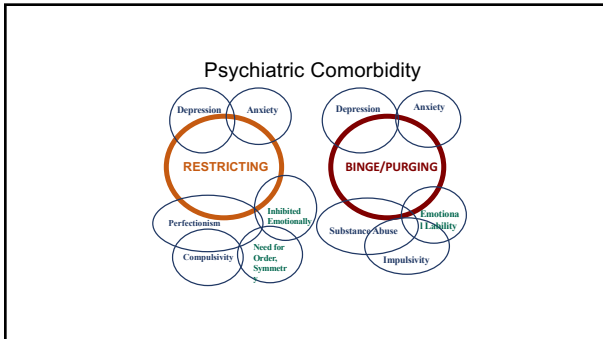
Psychol Med 2007;37:1075-1084; *IED* 2008;41:143-152; *Psychiatr Res* 2004;127:259-266; *Psychol Bull* 2007;133:976-1006



Malnourishment messes up the brain "Starvation brain"

- When someone is ENERGY DEFICIENT, the body starts to go into hibernation to conserve energy (think: Bears in hibernation)
- Minnesota Starvation Study (1940s)
- After a few weeks of seriously reduced diet, the men in the experiment:
 - Became obsessed with food; its all they thought or talked about
 - Often pored over cookery books, images and descriptions of foods
 - Became irritable, egocentric and depressed
 - Lost their sense of humor and isolated from others





These are extremely serious illnesses

- Best prognosis: early identification, long-term follow up
- 4-5% mortality across all EDs
 - Highest in AN
 - AN: 20% by suicide
- Anorexia Nervosa
 - 50% recovery
 - 20% chronicity
- Bulimia Nervosa
 - 50% recovery
 - 25% chronicity

Slide 4 of 4 | Evidence-Based Practice, 2015-2020 | Adaptation of "The Best Interest of the Patient" by the American Psychiatric Association, 2013. All rights reserved. © 2015 American Psychiatric Association. All rights reserved.

Science Lesson...

- Eating disorders are serious brain-based illnesses AND treatable
- Our knowledge that the brain is operating differently in eating disorder patients can help families respond with less frustration
 - it can help to understand that this is not a set of choices or lack of motivation to change.
- No one, including the patient, is at fault.
- Families need to focus on helping the patient regain their health through normal eating, providing a warm and supportive family environment, and working with a clinical team with the most recent training and expertise.

DIAGNOSIS & Assessment
Changing the landscape of eating disorders management by facilitating earlier intervention and care

What do you think? Have you heard this?

- "Her BMI is normal. There is nothing to worry about"
- "She is eating 3 meals and 3 snacks a day. Her eating is not the problem."
- "Wow. That is way too much food."
- "Her vital signs and laboratory tests were normal in my office this afternoon. She cannot be that sick."
- "She is fine from a medical point of view. Talk to her therapist about what she thinks."
- "I'm not sure these patients ever get better"

DerMarderosian, et al., 2018

A Diverse Array of Clinical Vignettes

- An 11-year-old boy with autism, weight loss, and picky eating
- A 12-year-old girl with body image concerns and questions about dieting
- A 15-year-old boy with obesity, binge episodes, and secretive eating
- A 17-year-old girl with female athlete triad
- A 32-year-old man with Type 1 diabetes, restrictive eating and insulin omission
- A 20-year-old college athlete with anorexia nervosa in remission
- A 40-year-old woman with severe chronic anorexia nervosa and malnutrition

The SWAG Effect: Disordered Eating's Deadliest Myth

THE BLOG [HELEN EDLINA ANDREAS](#)

The longer we believe only skinny, white, affluent girls suffer from eating disorders, the more we isolate an entire community of not-skinny, not-white, not-rich, not-so-young, decidedly-not-female human beings, who suffer, not only with the soul-sucking burden that is an eating disorder, but with the belief they can't possibly "have" what's killing them.

- Despite SWAG myth, eating disorders are prevalent (though underdiagnosed) across racial/ethnic groups and socioeconomic levels
- Males account for significant proportion of cases (particularly in anorexia nervosa)
- Prevalence increasing more rapidly for individuals from lower income backgrounds, males, and transgender individuals
- Greater increases in Medicaid (26%) than private insurance eating disorder hospitalizations (18%) totaling \$277M

Accurso et al., 2021; Deloitte Access Economics, 2020; Suokas et al., 2013; Zhao & Encinosa, 2020

Under-recognized and marginalized populations can present with more severe eating disorders

- Non-Whites are less likely to be diagnosed/treated
- Transgender individuals, gay males are at increased risk
- Atypical Anorexia Nervosa is often overlooked
- From 1999-2009 hospitalizations went up among
 - Males (by 53%)
 - 45-65 yo (by 88%)

Murray et al. Int J Eat Disord. 2015; 48(2): 140-145; Gordon et al. Am J Orthop. 2016; 42(6): 1001-1005; Diner et al. J Am Acad Health Syst. 2012; 17(2): 201-205; Zhou et al. J Acad Consultat Dev Med. 2013; 17(4): 395-399; Parker, L.L., Hergler, L.A. Eating disorders and disordered eating behaviors in the LGBT population: A review of the literature. J Eat Disord. 2015; 31: 1059-1070.


Eating Disorder Diagnosis: Down the Rabbit Hole

- AN
- BN
- ARFID
- BED
- OSFED

Anorexia Nervosa

- Restriction of food intake leading to weight loss, or maintenance of weight < 85% of ideal body weight (BMI<17.5)
- Fear of fatness or weight gain
- Distorted body image
- **Restricting type:** no binge behavior
- **Binge/Purge type:** binge purge behavior in setting of low weight or weight loss

DSM-V



Bulimia Nervosa

- Binge eating (at least once per week for at least 3 months)
 - Discrete period of time (2h)
 - Definitively more food consumed than appropriate (>2000 kcal)
- Sense of lack of control with eating behavior
- Purging or other compensatory behaviors to avoid weight gain/promote weight loss

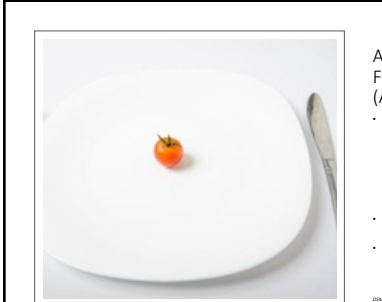
DSM-V



Binge Eating Disorder

- Newly articulated as part of DSM-V
- Recurring episodes of binge eating
- Must meet at least three of the following:
 - Eating more quickly than "normal"
 - Eating until so full that it is uncomfortable
 - Eating large amounts when not hungry
 - Eating alone because of embarrassment about volume
 - Feeling negative emotions about binge (disgust, depression, guilt)
- Distressed emotions around eating
- Binges occur at least once per week for at least 3 months
- Different from Bulimia: no recurrent behaviors to avoid weight gain

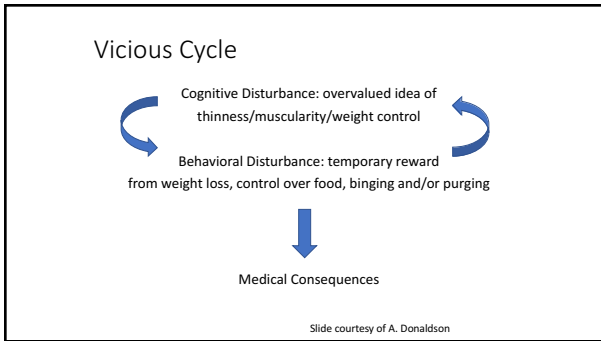
DSM-V

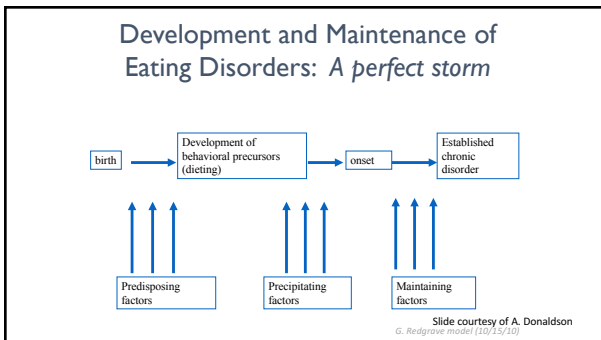


Avoidant/Restrictive Food Intake Disorder (ARFID)

- An eating or feeding disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with at least one of the following:
 - Significant weight loss, or failure to gain developmentally appropriate weight
 - Significant nutritional deficiency
 - Dependence on enteral feeding or oral nutritional supplements
 - Marked interference with psychosocial functioning
- The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no associated body image disturbance
- The disturbance is not better explained by
 - lack of available food
 - associated culturally sanctioned practice
 - attributable to/better explained by concurrent medical or psychiatric condition

DSM-V





Focus on the "BIG B"

It is because of these **self-sustaining factors** that initial treatment must focus on stopping the eating disorder **BEHAVIOR** rather than exploring predisposing and precipitating factors

Your unique role (yes, YOU!)

- YOU are uniquely situated for ED assessment
 - Know the patient
 - Know the family
- Medical and Behavioral Health providers can greatly impact ED prognosis through:
 - Early identification
 - Care coordination when higher level of support is needed
 - Interdisciplinary collaboration
 - Close monitoring
 - Long-term follow up

Slide courtesy of A. Donaldson

"I'm with my client and it becomes clear I'm dealing with some sort of ED, what are the questions I really want to get in my history?"

SCOFF QUESTIONNAIRE

- Do you make yourself sick (vomit) because you feel uncomfortably full?
- Do you worry you have lost control over how much you eat?
- Have you lost more than one stone (14lbs) over the last 3 months?
- Do you believe yourself to be fat when others say you are thin?
 - Would you say that food dominates your life?

*****One point for every yes, a score of two or more warrants further evaluation*****

QUESTIONS 1-12. Please circle the appropriate response for each question. Remember that the questions only refer to the past 28 days.

On how many of the past 28 days:

	Not at all	1-2 days	3-5 days	6-10 days	11-15 days	16-20 days	21-27 days	Every day
1. Have you been deliberately trying to limit the amount of food you eat or restrict your diet because you are afraid of gaining weight or are afraid of becoming fat?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Have you gone for long periods of time (30 minutes or more) without eating anything at all or eating only a few sips of liquid or only a few bites of food?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Have you tried to restrict how much you eat by eating only small portions or by eating only certain foods?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Have you tried to restrict how much you eat by eating only certain foods or by eating only certain times of the day?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Have you had a specific desire to keep an object (not just the act of swallowing) your throat or chest open?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Have you had a specific desire to vomit or to induce vomiting?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Have you had a specific desire to eat large amounts of food or to eat until you are uncomfortably full or until you are physically uncomfortable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Eating Disorder examination questionnaire (EDE-Q)

Assessing for an Eating Disorder: *Becoming a detective*

- Consider including **feedback** from someone within the support system
- Identify **historical eating patterns**: does the individual have a history of picky eating, overeating, skipping certain meals
- Identify when concerns regarding eating began, with a **step-by-step review of changes in eating behaviors**, including change in types of food, amounts consumed and whether there is concern for skipping meals. Have they become a vegetarian, vegan, cut out grains or dairy? Are there foods that were previously enjoyed that they are no longer eating?

Assessment, continued *Becoming a detective*

- Concise current meal plan ("**food recall**"): *"From the time you get up until the time you go to bed, what do you eat."*
- Be sure to ask if they are eating the same or different meals than those around them, portion sizes, how much of the meals they complete, if they are eating with the family, friends or in their room, etc
- Details about low fat, fat free foods, etc.
- **Fluctuation in weight**

Assessment, continued
Becoming a detective

- **Calorie counting**, measuring foods
- **Odd food rituals and rules** including temperature of foods, time of day allow self to eat, picking food into small pieces, taking long periods of time to complete, eating in certain order, foods touching
- Any evidence of **binge, purge**, vomiting, laxative, diet pills, diuretics (good opportunity for psycho education)
- **Exercise**: type, amount, aimed at wt loss. Include gym, organized sports, running, etc. What happens if they are injured? Rest days?

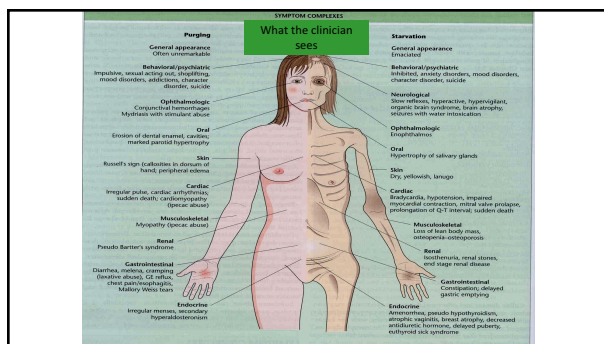
Assessment, continued
Becoming a detective

- **Body image**- comments about appearance/ wt of self and others, body checking
- **Shape/size of peers**
- **Culture of food and dieting** in the family and peer circle
- **Excessive water/caffeine** intake or gum chewing
- **Access to online pro-ana/pro-mia** websites, calorie counters, fitness apps; "influencers," esp Tik Tok
- **Mood changes/ irritability** with food discussions
- **Drop in grades/taking longer** to complete work



Nutrition-Specific Assessment

- **Anthropometric History**
 - Weight & height history
 - Including highest, lowest & goal weight
 - Frequency of weighing self
- Access growth charts in adolescents





There's a problem, so now what?
Calling it what it is

- Even if unsure, talk about the ED as a possible diagnosis.
- Be prepared that some families may have difficulty hearing this
- We NEED to be having these conversations
- "I'm concerned for these reasons..."
- "This is what multidisciplinary treatment can look like..."
- Talk next steps
- If things continue to worsen, refer to HEDC or HLOC


Goals of Treatment

Short Term:
Nutrition First

- Medical stabilization
- Weight restoration if underweight

Longer-term:
Insight Later

- Establish/maintain normal eating behaviors
- Cognitive rehab/ REWIRING
- Return to normal developmental trajectory



Framing treatment

- Stigmatize the behavior, not the patient
- Counter demoralization & reduce blame
- Explore pro's/con's of behaviors in patient's life
- Build rapport and reinforce medical message
- Clear message about expectation for recovery
 - Patient/family must be ready to engage in care to succeed

Ramsay et al., 1999; McHugh 2000

Slide courtesy of A. Donaldson

Team Based Care: *It Takes a Village*

- Primary medical doctor
- Therapist and/or Psychiatrist
- Nutritionist (sometimes)
- Parents/ Caregivers
- Patient



The best outcomes for patients with eating disorders are associated with a collaborative approach by a interdisciplinary team.

As providers, we must talk to each other and to the families. A unified message is essential.

Support family,
set a plan, and
guide the family

- **WHAT TO DO:**
 - Act Now
 - Get Together
 - Focus on How, not Why
 - Stay Empowered- 1 step ahead/ take care of self
- **HOW TO DO IT:**
 - The 6 D's
 - Food is medicine
 - One bite at a time
 - Outsmart/ Outplay

The "D's" of Beating ED

- _____ Differentiate
- _____ Disobey
- _____ Disagree
- _____ Disconnect
- _____ Dig Deep
- _____ Discover

Work collaboratively
with families: *WHAT*

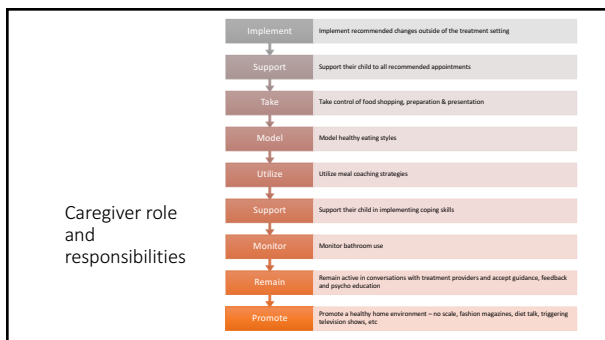
- Coaching supports to become expert on the ED and its treatment
- An individual with an ED is in an altered state even when they are otherwise quite bright and rationale (anosognosia)
- Treatment does not feel good
- Laser-like focus on ED behaviors
- Nutrition first, Insight later
- Treatment feels worse before it gets better (think exposure-based tx)
- You, as the caregivers, need to be part of the treatment



Work collaboratively with families: **HOW**

- Providing information, education and support for the patient and their family
- Including the patient's family in assessment, engagement, treatment and recovery support
- Engaging the family in collaborative decision making to enhance motivation for change
- Identifying and responding to engagement difficulties and ambivalence about treatment
- Modelling an understanding and supportive attitude
- Being aware of your personal attitudes, values and beliefs (e.g. re: body shape) so that you can manage countertransference or collusion with the patient

"Strong Back; Soft Front"





ED Treatment Resources

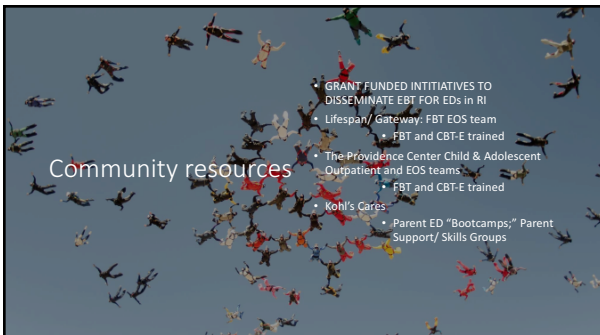
- Recommended books for medical providers: Mehler and Andersen, "Eating Disorders: a Guide to Medical Care and Complications" (2010); Jennifer Gaudiani, "Sick Enough" (2019)
- Recommended books for providers/care-givers: Life Without Ed; Brave Girl Eating; Help Your Teenager Beat and Eating Disorder; Sick Enough; How to Nourish Your Child Through an Eating Disorder; Anorexia and other eating disorders: How to help your child eat well and be well
- National Eating Disorder Association (NEDA): <https://www.nationaleatingdisorder.org/>
- Academy for Eating Disorders: <https://www.aedweb.org/>
- Families Empowered and Supporting Treatment of Eating Disorders: <https://www.familiesempowered.org/>
- Meal coaching video posted on youtube: "Eating Disorders Meal Support: Helpful Approaches for Families"
- International Association of Eating Disorder Providers, RI Chapter



**brave
girl
eating**

Parent Toolkit

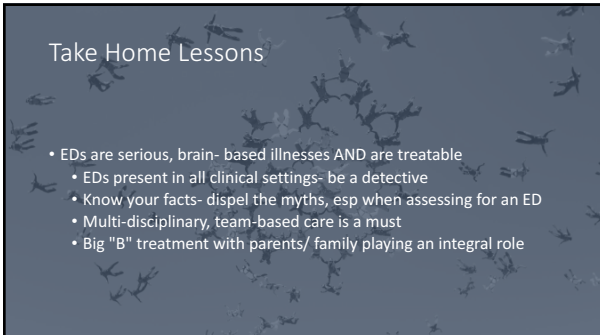
- AED's Nine Truths
- F.E.A.S.T. Family Guides
 - "First 30 Days"
- Rebecca Peebles Video
- How to Help Your Teen Beat an ED book
- Brave Girl Eating & Feeding Your Anorexic books
- Eva Musby book & website



Community resources

GRANT FUNDED INITIATIVES TO DISSEMINATE EBT FOR EDs in RI

- Lifespan/ Gateway: FBT EOS team
 - FBT and CBT-E trained
- The Providence Center Child & Adolescent Outpatient and EOS teams
 - FBT and CBT-E trained
- Kohl's Cares
 - Parent ED "Bootcamps;" Parent Support/ Skills Groups



Take Home Lessons

- EDs are serious, brain- based illnesses AND are treatable
- EDs present in all clinical settings- be a detective
- Know your facts- dispel the myths, esp when assessing for an ED
- Multi-disciplinary, team-based care is a must
- Big "B" treatment with parents/ family playing an integral role
