***Note**: Our teams are working on a more robust section on Eating Disorders on our website. This PDF is meant to be a temporary resource, please check back often for the updated Eating Disorder Toolkit on childrenswi.org.*

PEDIATRIC EATING DISORDER TOOLKIT – MEDICAL PROVIDERS

Medical Disclaimer

Medicine is a dynamic science; as research and clinical experience enhance and inform the practice of medicine, changes in treatment protocols and drug therapies are required. The authors have checked with sources believed to be reliable in their effort to provide information that is complete and generally in accord with standards accepted at the time of publication. However, because of the possibility of human error and changes in medical science, neither the authors nor Children's Hospital and Health System, Inc. nor any other party involved in the preparation of this work warrant that the information contained in this work is in every respect accurate or complete, and they are not responsible for any errors in, omissions from, or results obtained from the use of this information. Readers are encouraged to confirm the information contained in this work with other sources.

This pediatric eating disorder toolkit, is intended as a resource for Registered Dietitians, Mental Health Providers, and Medical Providers that are seeing patients with eating disorders due to a lack or limited availability of specialized treatment providers available to patients/families. This is not a comprehensive treatment guide. The goal of this pediatric eating disorder toolkit is to promote key areas of assessment and follow up care until more specialized care is established. Please note that if specialized eating disorder care providers exist in or near your community, it is recommended to connect patients and families to these resources as quickly as possible.

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General Information

MULTIDISCIPLINARY TREATMENT TEAM

Treating eating disorders happens best under the guidance of a multidisciplinary treatment team:

- Primary medical provider
- Mental health therapist (LPC, LCSW, Psychologist), preferably trained in eating disorders
- Registered dietitian (RD), preferably trained in eating disorders
- Family therapist (if recommended)
- Psychiatrist (if recommended)

It is imperative that each member of the treatment team be willing and able to collaborate care with the other disciplines in a timely manner to ensure the best and most consistent care across all disciplines.

Unfortunately, sometimes it is not possible for all treatment team members to be part of the care team. This can be for a variety of reasons such as:

- Lack of providers in a specific geographic area.
  - If there is a lack of providers in your geographic area, please investigate virtual resources or referrals for your patients. There are many excellent virtual resources that could be assembled to form a full treatment team. Another great option is getting case consultation from a certified eating disorder specialist in that particular discipline. To connect with a Certified Eating Disorder Specialist visit the International Association of Eating Disorder Professionals website at iaedp.com and click on the link "Find An Eating Disorder Professional".
- Lack of insurance coverage for a particular specialty area.
  - It is advised that patients/families check with their health insurance company on coverage for each of these specialty areas for the treatment of an eating disorder.
- Patient/family may not want a particular discipline added to their loved ones' treatment team.
  - This can be for a variety of reasons. We encourage this be reviewed on a case-by-case basis. In most instances a full treatment team offers the best outcomes.

DIAGNOSTIC CRITERIA

Diagnosis of an eating disorder can be made by a medical provider, therapist, psychologist, or psychiatrist. These diagnostic criteria are provided for educational purposes. Please refer patient to an evaluation with a specialist if there are concerns for restricted or avoidant eating. For a complete listing (along with criteria) for feeding and eating disorders, please refer to DSM-5 (Diagnostic and Statistical Manual of Mental Disorders).

Avoidant Restrictive Food Intake Disorder (ARFID)

Avoidant/restrictive food intake disorder (ARFID) includes restrictive eating due to one or more of the following:

- Low appetite and lack of interest in eating or food.
- Extreme food avoidance based on sensory characteristics of foods e.g. texture, appearance, color, smell.
- Anxiety or concern about consequences of eating, such as fear of choking, nausea, vomiting, constipation, an allergic reaction, etc.

The diagnosis of ARFID requires that difficulties with eating are associated with one or more of the following:

- Significant weight loss (or failure to achieve expected weight gain in children).
- Significant nutritional deficiency.
- The need to rely on a feeding tube or oral nutritional supplements to maintain sufficient nutrition intake.
- Interference with social functioning (such as inability to eat with others).

Note: Consider SLP and/or OT referral when there are swallowing and/or sensory concerns.

Anorexia Nervosa

Anorexia nervosa includes the following symptoms:

- Caloric restriction leading to underweight OR weight that is less than what is expected for age.
- Intense fear of gaining weight OR persistent behavior that interferes with weight gain.
- Body image disturbance OR undue influence of body weight or shape on self-evaluation, OR lack of recognition of seriousness of low body weight.

Atypical Anorexia Nervosa

Atypical anorexia has the same criteria as anorexia nervosa with the exception of a BMI that is normal to above normal ranges despite significant weight loss.

Bulimia Nervosa

- Recurrent episodes of binging and purging at least once per week (purging may include self-induced vomiting, fasting, excessive exercise, laxative or diuretic misuse).

Binge Eating Disorder

- Discrete episodes of binge eating that occur at least once per week for 3 months.
- Episodes must include eating more than another person would in similar circumstances, and sense of loss of control.
- Episode have at least one of the following features: eating in secrecy, eating rapidly, eating until uncomfortably full, eating when not hungry, or guilt/shame afterward.

SYMPTOMS

Source of information: National Eating Disorders: https://www.nationaleatingdisorders.org/warning-signs-and-symptoms. Please note: this is *not* a checklist but instead a list of symptoms that could be present with some eating disorders.

- Preoccupation with dieting/fad dieting, weight or weight loss, body shape and size
- Frequent mirror checking for perceived appearance flaws
- Preoccupation with food or food avoidance, calories, carbohydrates, sugar, fat
- Overly strict food rules
- Refusal to eat certain foods or up to whole food groups, or foods previously enjoyed
- Cutting out an increasing number of foods or food groups
- Increased concern and time spent thinking about "health" of ingredients, what is deemed "health, clean, or pure", high distress when healthy foods aren't available, follow and fixated on health/clean eating
    - For more information, search **ORTHOREXIA** on the National Eating Disorders website
- Withdrawal from friends/family, no longer participating in things use to enjoy doing
- Eating/behavior rituals with eating (certain utensils, certain order of eating, slow/fast eating pace, preference to eat alone)
- Excessive or rigid exercise regime (despite weather, sickness, injury, fatigue), need to 'burn' or get rid of calories, intense feelings if unable to exercise, exercise used to manage emotions, discomfort with rest or inactivity, exercise for permission to eat, exercising in secret, intense feelings involving physical activity
- Feelings of disgust, shame, guilt overeating, low self-esteem
- Eating of non-food items
- Small portions or skipping meals
- Gastrointestinal concerns (constipation, diarrhea, vomiting, acid reflux, bloating, stomach cramping, getting full quickly)
- Menstrual irregularities (light, inconsistent, irregular, amenorrhea, missing periods without the use of hormone contraceptives)
- Growth chart percentile changes, weight fluctuations
- Mood swings, difficulty concentrating, feelings of disgust, shame, guilt over eating, low self-esteem, withdrawal from friends and or family, depression and/or anxiety
- Low appetite, limited preferred foods, and lack of interest in eating or food. Extreme food avoidance based on sensory characteristics of foods e.g. texture, appearance, color, smell. Anxiety or concern about consequences of eating, such as fear of choking, nausea, vomiting, constipation, an allergic reaction, etc.

MEDICAL FINDINGS

Please note: this is *not* a checklist but instead a list of medical findings that could be present with some eating disorders.

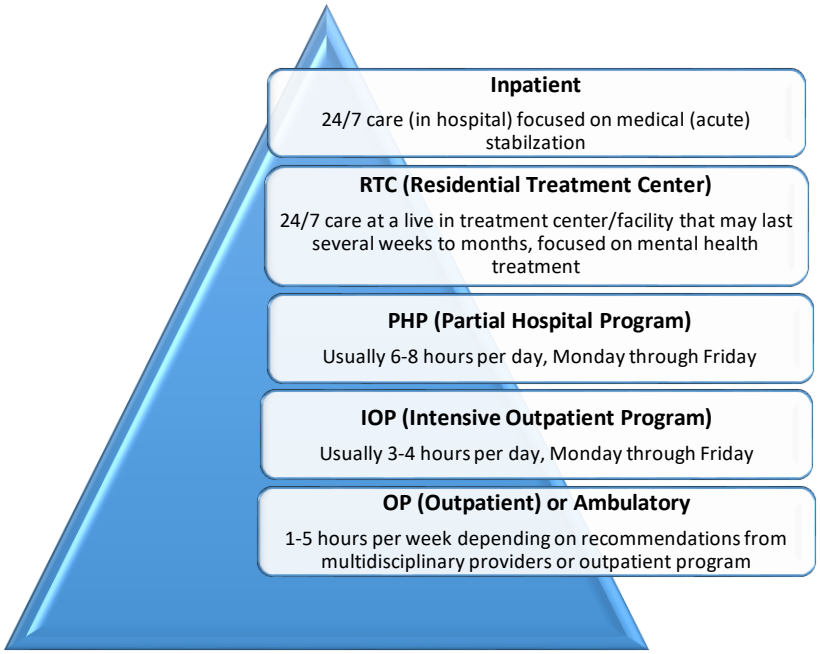
- Orthostatic intolerance symptoms, lightheadedness, dizzy upon standing, fainting
- ECG, bradycardia, irregular heart patterns
- Muscle weakness
- Cold intolerance (feeling cold all the time, extremities cold and mottled, dressing in layers-can also be to hide weight loss or self-harm)
- Difficulties with sleep or increase in sleep pattern
- Slow/poor wound healing, dry skin, hair that is dry and/or falling out, yellow/orange skin, new growth of fine body hair (lanugo), brittle nails, cuts/calluses across tops of finger joints (from self-induced vomiting)

- GI: delayed gastric emptying, slow intestinal transit time, nausea, bloating, postprandial fullness, GERD, constipation, esophageal mucosal damage, Mallory-Weiss tears, superior mesenteric artery (SMA) syndrome, hepatic transaminase concentrations and coagulation times can be elevated
- Weight loss with or without the fear of weight gain or body image concerns
- Dental problems (erosion of enamel, cavities, tooth sensitivity, swelling around salivary glands, discoloration of teeth)
- Swelling (edema)
- Frequent sickness (impaired immune system)
- Re-chewing, re-swallowing or spitting out food
- In the presence of diabetes: neglect and/or secrecy of diabetes cares, not taking medication as prescribed, infrequently filled prescriptions, missing diabetes related appointments, fear of insulin causing weight gain, restricting certain foods, A1c of 9.0 or higher on continuous basis, fear of low or high blood sugars, inconsistent meter readings, restriction of certain foods or food groups to lower insulin usage, deteriorating or blurry vision, fatigue/lethargy, frequent bladder and/or yeast infections, persistent thirst and frequent urination, nausea and/or vomiting, unexplained weight loss, low sodium and/or potassium, DKA or near DKA episodes, in addition to any of the other symptoms described above
- Renal and electrolyte effects: dehydration, electrolyte abnormalities, edema.
- Endocrine: euthyroid sick syndrome, hypercortisolemia, amenorrhea, low testosterone, smaller testicular volumes, growth delays/cessation, low bone density
- Abnormal laboratory and electrolyte possible findings:
    - CBC, CMP, Amylase, TSH, urinalysis, electrolytes.
    - **Labs associated with concern for refeeding syndrome:**
        - Low Potassium - Hypokalemia (< 3.0 mEq/L)
        - Low Phosphorus – Hypophosphatemia (< 2.5 mg/dL)
        - Low Magnesium – Hypomagnesaemia (less than 1.46 mg/dL)
    - **Labs Associated with Concern for Purging**

Method of Purging	Serum Levels					Urine Levels		
	Sodium	***Potassium***	***Chloride***	***Bicarbonate***	***pH***	***Sodium***	***Potassium***	***Chloride***
Vomiting	Increased, decreased or normal	Decreased	Decreased	Increased	Increased	Decreased	Decreased	Decreased
Laxatives	Increased or normal	Decreased	Increased or Decreased	Decreased or Increased	Decreased or Increased	Decreased	Decreased	Normal or decreased
Diuretics	Decreased or Normal	Decreased	Decreased	Increased	Increased	Increased	Increased	Increased

Mehler PS. Clinical practice. Bulimia nervosa. N Engl J Med. 2003 Aug 28;349(9):875-81. doi: 10.1056/NEJMcp022813. PMID: 12944574.

LEVELS OF CARE (LOC)



Treatment options in or near Wisconsin (updated: 1/30/24)	Locations	Ages	Pay Acceptance
OUTPATIENT			
Connected for Kids – Bellin Adolescent Medicine https://www.bellin.org/services_programs/child-adolescent-health/adolescent-care	De Pere (2024)-Green Bay (2025)	Ages 10+ (through college)	Accepts most insurances including Medicaid
Equip https://equip.health	Virtual FBT program	Ages 6+, including adults	Commercial insurance or self-pay only
Thedacare – physician referral needed from any clinic/hsp for eating disorder dietitian services	Appleton	Children, adolescents, adults	Commercial insurance, RD services not covered for patients with Medicaid (financial assistance may be available)
Local (individual) providers to form treatment team: PCP, Therapist, Registered Dietitian	In person and virtual	Varies	Varies
IOP (INTENSIVE OUTPATIENT PROGRAM)			
Monte Nido Chicago Eating Disorder Day Treatment: Monte Nido Chicago Day Treatment web page	Lombard, IL	Ages 11+	Newer program so still working on insurance contracting. But likely will be in network with BCBS and Aetna first
Rogers Behavioral Health - Child/Adolescent https://rogersbh.org/what-we-treat/eating-disorders-treatment)	Oconomowoc, WI	(internal step-down only), Ages 6+	Call: 800-767-4411
Rogers Behavioral Health - Adult	Oconomowoc, WI	Ages 18+	Call: 800-767-4411

Eating Recovery Center (ERC) – 3 days per week for 3 hours a day. Patients also will see their outpatient providers while in IOP so that they have individual support while being in IOP group support. https://www.eatingrecoverycenter.com/	Northbrook, IL	Ages 10+	Commercial insurance, not WI state insurance.
PHP (PARTIAL HOSPITAL PROGRAM)			
Monte Nido Chicago Eating Disorder Day Treatment: Monte Nido Chicago Day Treatment web page	Lombard, IL	Ages 11+	Newer program so still working on insurance contracting. But likely will be in network with BCBS and Aetna first
Rogers Behavioral Health – Child/Adolescent	Oconomowoc, WI	Ages 6+	Call: 800-767-4411
Rogers Behavioral Health – Adult	Oconomowoc, Appleton, Madison, WI	Ages 18+	Call: 800-767-4411
Eating Recovery Center (ERC) – 7 days per week. Offer housing at some locations but also have contract with hotels and Ronald McDonald.	Northbrook, IL	Ages 10+	Commercial insurance, not WI state insurance.
RESIDENTIAL			
Rogers Behavioral Health - Adolescent	Oconomowoc	Ages 12-17	Call: 800-767-4411
Rogers Behavioral Health - Adult	Oconomowoc	Ages 18+	Call: 800-767-4411
Eating Recovery Center (ERC)	Northbrook, IL	Ages 10+	Commercial insurance, not WI MA
Clementine Clementine Naperville Virtual Tour https://clementineprograms.com/program-locations/clementine-naperville/	Naperville, IL	Ages 11-17, female identifying adolescents	BCBS, AETNA in network (can do look into SCA's and out of network)
INPATIENT			
Children's Wisconsin – Adolescent Medicine (acute medical stabilization)	Milwaukee, WI	Ages 9+	Accepts most insurances including Medicaid
Eating Recovery Center (ERC) – ACUTE (acute medical stabilization)	Denver, CO	Ages 15+	Commercial insurance, not WI MA
Rogers Behavioral Health	Oconomowoc	Ages 8+	Call: 800-767-4411

WEIGHTS

Patient's weight

Patients with eating disorders are often highly fixated on their weight and body image. Desired weight loss is a common driver behind patients' decision to restrict food intake. As a result, it may be in a patient's best interest to:

- Refrain from discussing weight loss or gain.
- Encourage removal of scales at home (or at least removal of patient access to scales at home).
- At medical visits obtain "closed" weights (weight number is kept "closed" or unknown to patient)
- Omit weights on any documents provided to patients during visits.
- Focus on other health markers when making nutrition changes. For example, increased energy, improved mood, stronger hair or nails, decreased muscle fatigue during sports, etc.
- Please note:
    - Exposure and Response Prevention (ERP) is a treatment modality where use of scale/weight exposure may therapeutically be recommended.
    - Family-Based Treatment (FBT) traditionally uses open weights in therapeutically recommended ways.

"Closed" weight at medical office

IMPORTANT: keep the weight/number "closed" (unknown to patient).

1. Encourage the use of bathroom prior to weight check.
2. Take off shoes and any heavy clothing patient is wearing, this includes jackets, sweatshirts/sweaters, and any items in pockets (cellphones). It's okay to weigh patient wearing a light layer of clothing. If treatment team or caregiver(s) suspect that patient is hiding weighted items in pockets, bras, and underwear then collecting an examination gown weight would be encouraged (pending clinic protocols).
3. Keep your patient from touching nearby furniture or walls.
4. Place a light covering over the "number" screen (a post-it note typically works well), so that only clinician can see the number.
5. Have patient get on the scale backwards.
6. Do's:
    - Omit weights on any documents provided to patient during visit.
    - Refrain from discussing weight at all with patient (leave this up to treatment team to deem what is best for each individual patient).
    - Provide caregivers with weight information separately from the patient.

Children's Wisconsin: *Closed weights within clinic*	
✓ Patient takes off everything except underpants	✓ Weighed with back to scale
✓ Change into 2 gowns	✓ Try to use the same scale for every visit

Telehealth

In preparation for a telehealth visit, an updated weight check should be completed ideally the day of, or up to 2 days prior to the telehealth visit. This updated weight could be obtained through a "weight check" at the primary care office or at home, if a caregiver has access to an accurate home scale (see instructions below). In either situation, it is recommended that the weight/number is "closed".

"Closed" weight at home

If family has an accurate home scale, a closed weight check can be completed at home by following these steps. IMPORTANT: keep the weight/number "closed" (unknown to patient).

1. Encourage the use of bathroom prior to weight check.
2. Take off shoes and any heavy clothing your child is wearing. This includes jackets, sweatshirts or sweaters. It's OK to weigh your child wearing a light layer of clothing.
3. Keep your child from touching nearby furniture or walls.
4. Use the scale on a solid ground (tile/vinyl/laminate/cement flooring; not carpeting).
5. Place a light covering over the "number" screen (a post-it note typically works well), so that only parent/guardian/caregiver can see the number.
6. Have your child get on the scale backwards.
7. Return the scale to a location where the child does not have access to the scale to weigh themselves.
8. Communicate updated weight privately with healthcare team. Caution should be exercised if the child has access to the electronic medical records for this data to be seen in a chart message.
9. Refrain from disclosing weight or weight trends at all with the child; encourage them to speak directly to treatment team with questions and/or concerns.

ORTHOSTATIC VITAL CHECKS

1. Heart rate (pulse) and blood pressure obtained **after 5 minutes** of supine rest
2. And repeated **after 2 minutes** of standing
3. Orthostatic changes:

   Blood pressure: sustained **DROP** of blood pressure
   - Systolic BP >20 mm Hg
   - Diastolic BP >10 mm Hg

   Heart rate (pulse): sustained **INCREASE** of pulse
   - >40 bpm in teens aged <19 YO

PHYSICAL ACTIVITY

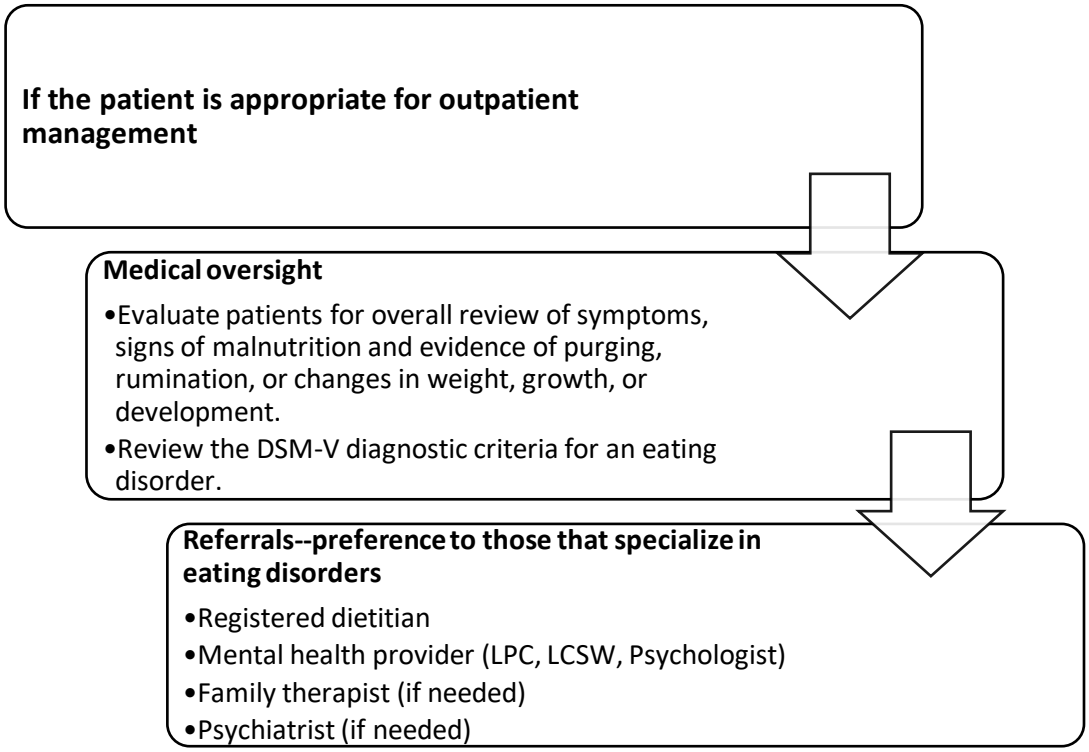
The Medical Provider, Mental Health Provider, and RD will ideally work collaboratively to determine if the patient is safe to engage in physical activity (medically, mentally, and emotionally). It is important to understand the role physical activity plays in an individual's life and eating disorder. Often, physical activity needs to be restricted initially and then gradually reincorporated with patient safety (medically, mentally and emotionally) at the forefront of any decisions made by the treatment team. If physical activity was used by the eating disorder, a therapist can be very helpful in this process of reintroduction.

Medical Providers

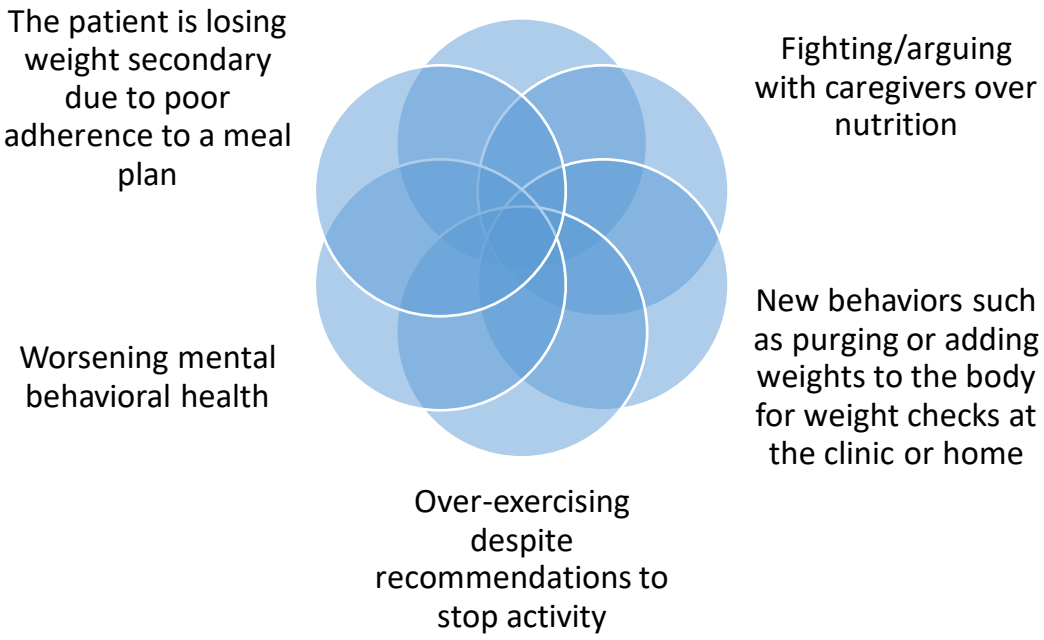
OUTPATIENT MEDICAL APPOINTMENTS

Inquire about during medical appointment

Thoughts	Behaviors	Previous and current treatment
•Fear of gaining weight •Fear of being overweight •Fear of having fat on body •Guilt/shame after eating •Time precoccupied with food/body image thoughts •Body image	•Restricting •Avoiding certain foods •Rituals around meals/preparation •Calorie counting •Overeating/binge eating •Compensatory purging (self-induced vomiting, exercise, laxatives/diruetics) •Current exercise/activity level •Body checking •Weighing •Response to nutrition encouragment	•Eating disorder •Other co-morbiities



When to recommend a higher level of care



If patient needs HIGHER level of care

→ Follow patients weekly to bi-weekly while awaiting acceptance to higher level of mental behavioral health

→ Weights and vital (orthostatic BP and pulse) checks

Children's Wisconsin: (inpatient) hospital admission criteria for medical stabilization

if one or more criteria present

Malnutrition

- Weight </=75% of ideal body weight (IBW) (calculation following)
- Patient eating <500 cal/day for last 3 days
- Rapid weight loss of >5% of body weight within 10 days before admission
- Acute food refusal

Cardiac Abnormalities

- Heart rate <45/min
- Cardiac arrhythmias, including prolonged QTc (If prolonged QTc exists, the patient will be admitted to the ICU for cardiac monitoring)
- Hypotension for age and sex or blood pressure <80/50mm hg
- Orthostatic changes in pulse (sustained increased >40 bpm in teens aged <19 years or sustained drop of blood pressure >20 mmHg systolic or >10 mmHg diastolic)

Electrolyte Abnormalities

- Hypokalemia (<3.0 mEq/L) (If IV K+ is required, the patient will be admitted to the ICU)
- Hypophosphatemia (<2.5 mg/dL)
- Hypochloremia (<88 mEq/L)
- Metabolic Acidosis/ Ketosis

Hypothermia (temp. <96 F)

Acute medical complications of malnutrition (e.g., syncope, seizures, cardiac failure, pancreatitis, etc.)

Acute psychiatric emergencies (e.g., suicidal ideation, acute psychosis) leading to medical instability

Co-morbid diagnosis (e.g., severe depression, obsessive-compulsive disorder, severe family dysfunction) leading to medical instability

Failure of Outpatient Treatment leading to medical instability as noted above

Arrested growth and development*

Uncontrolled binge eating or purging

*Consider the following question: Are you expecting this aged child to lose weight or fall off the height curve? Example: 9-12 year old children may not fit the admission criteria but still may need to be admitted.

Children's Wisconsin: hospital admission

✓ **If the patient has been seen in the last 24 hours AND**

✓ **Meets the criteria for admission *(prior section)***

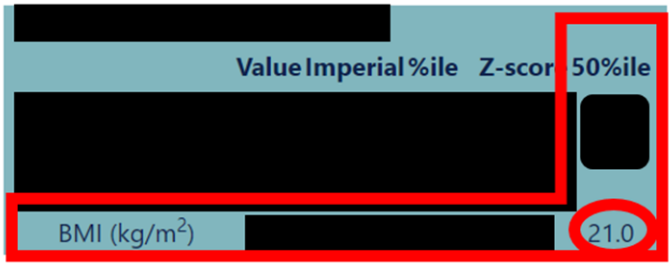
Referral for hospitalization goes through the CW referral line (for direct admits seen within the last 24 hours) or through Children's ED (if not seen within the last 24 hours)

Admission work-up (labs and tests)

1. CBC
2. CMP
3. Mg
4. Phosphate
5. TSH
6. Amylase
7. ESR
8. Pre-albumin
9. UA
10. EKG
11. Patient without prior eating disorder diagnosis: consider differential for presenting symptoms

Children's Wisconsin: calculation for "%IBW"

1. Input patient information into CDC Growth Calculator for 2 to 20 years: https://peditools.org/growthpedi/ and click "submit"
2. Locate BMI at the 50$^{\%ile}$ for age.



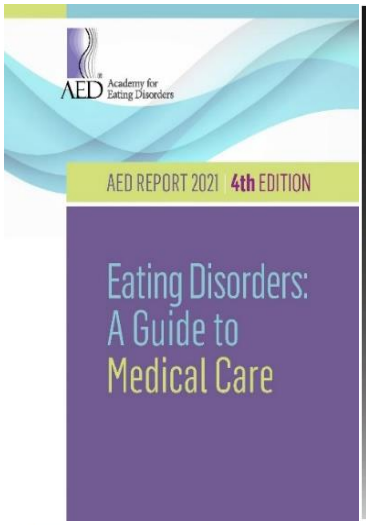
3. 50th%ile BMI x height (M^2) = **IBW(kg)**
4. Current weight (kg) / IBW (kg) x 100 = **%IBW**

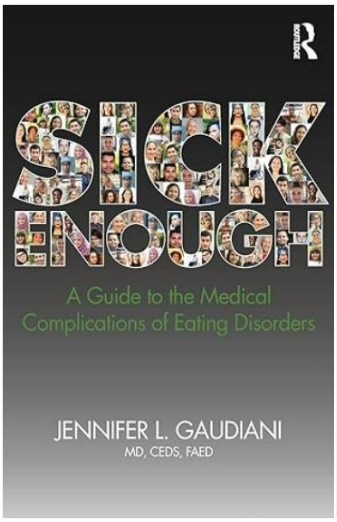
RESOURCES

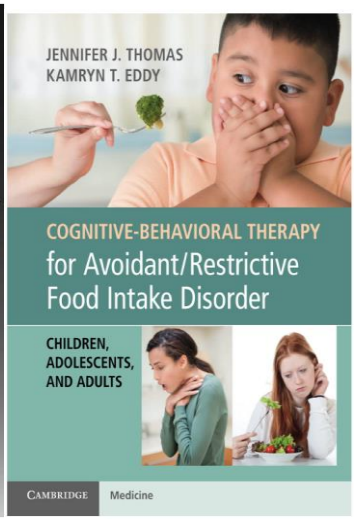
Caregiver website resources

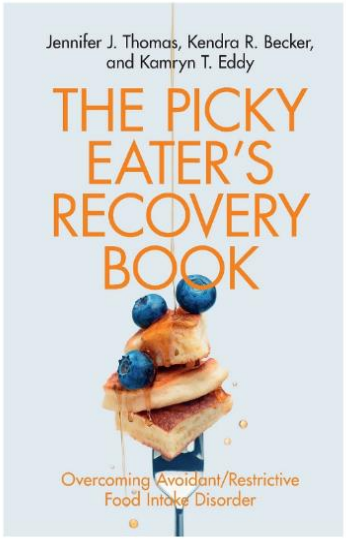
- http://www.parents-to-parents.org
- http://www.feast-ed.org/
- https://www.emilyprogram.com/for-families/resources-for-families/
- https://www.eatingrecoverycenter.com/resources/families
- https://www.nationaleatingdisorders.org/parent-toolkit

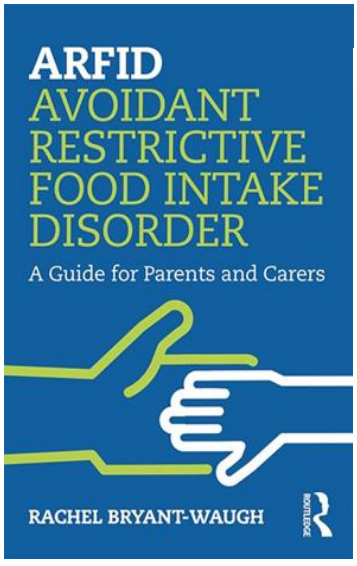
Book resources

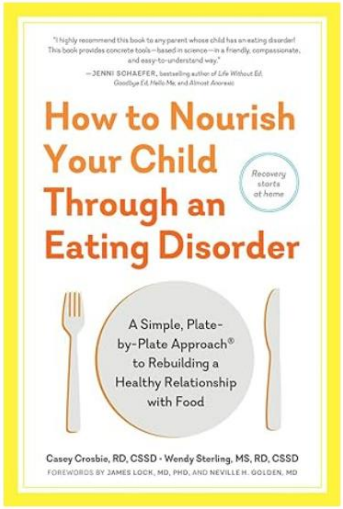


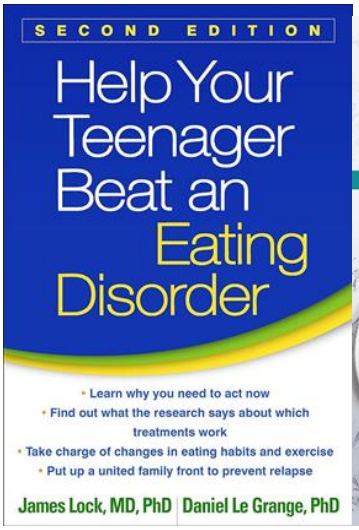


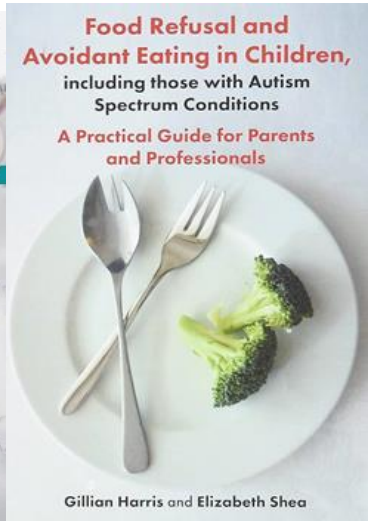


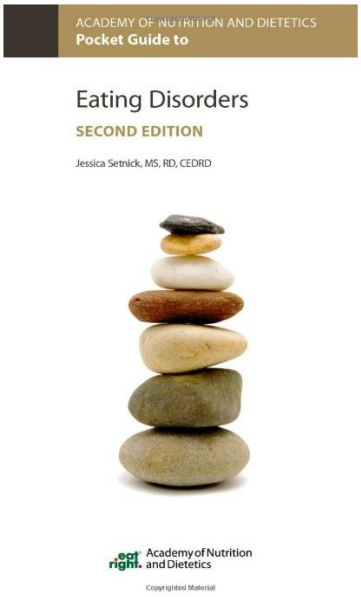


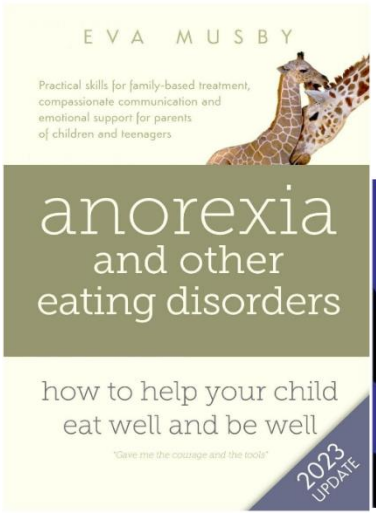


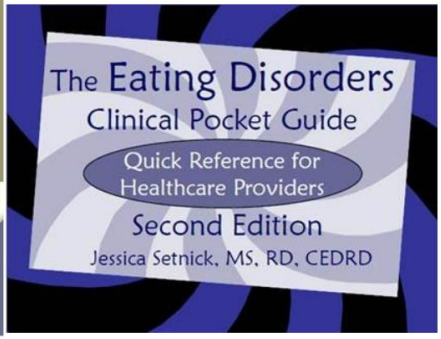












Resources for providers

- American Psychiatric Association (APA) Eating Disorder Practice Guidelines. Pocket book: https://eguideline.guidelinecentral.com/i/1492606-eating-disorders/0?
- Registered Dietitians additional online training: