JOHNS HOPKINS ALL CHILDREN'S HOSPITAL

Eating Disorder Clinical Pathway

Johns Hopkins All Children's Hospital

Eating Disorder Clinical Pathway

Table of Contents

- 1. Rationale
- 2. Background
- 3. Diagnosis
- 4. Clinical Management
- 5. Emergency Center
 - a. EC Pathway
 - b. EC Management
- 6. Admission
- 7. Inpatient
 - a. Inpatient Pathway
 - b. Inpatient Management
- 8. Discharge
- 9. Documentation Reminders
- 10. Outcome Measures
- 11. References
- 12. Clinical Pathways Team Information
- 13. Appendix A: Calculating Ideal Body Weight (IBW) and % of IBW
- 14. Appendix B: Text-Only Info for Caregivers Not for printing
- 15. Appendix C: Text-Only Info for Patient Not for printing
- 16. Appendix D: Tasks for Constant Patient Observer (CPO)
- Appendix E: PRINTABLE Constant Patient Observer (CPO)
 Checklist
- 18. <u>Appendix F: PRINTABLE (English) Patient & Caregiver Handouts</u>
- 19. <u>Appendix G: PRINTABLE (Spanish) Patient & Caregiver Handouts</u>
- 20. Appendix H: PRINTABLE Outpatient ED Clinic Handout

Updated: February 2023 Owners: Kimberly Collins, MD; Aaron Samide, MD

Johns Hopkins All Children's Hospital

Eating Disorder Clinical Pathway

Rationale:

This clinical pathway was developed by a consensus group of JHACH physicians and a multidisciplinary team to standardize the management of children hospitalized for suspected or confirmed eating disorders. It addresses the following clinical questions or problems:

- 1. The care plan goals for medical stabilization and nutritional resuscitation of a suspected or confirmed eating disorder
- 2. Admission criteria for a suspected eating disorder
- 3. Feeding plan for a patient with a suspected eating disorder
- 4. Treatment Team Communication
- 5. Discharge criteria

Background:

Eating disorders are complex illnesses that are becoming increasingly frequent among preadolescents and adolescents. These disorders are associated with serious biological, psychological, emotional, and sociological morbidity, as well as significant mortality, and can result from disturbance in eating behaviors, distortion of perceived body image, and obsessional thoughts and rituals. Early recognition and treatment are crucial to recovery.

Diagnosis:

The Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) provides the full diagnostic criteria for each of the following eating disorders commonly seen in children and adolescents:

Anorexia Nervosa is characterized by:

- Restriction of energy intake relative to requirements leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health.
- o Intense fear of gaining weight or becoming fat, even though underweight.
- Disturbance in the way one experiences one's body weight or shape; undue influence of body weight or shape on self-evaluation; or denial of the seriousness of current low body weight.
- People with Anorexia Nervosa, restricting type severely restrict how much food they eat and the types of food they consume. This may also be paired with excessive exercise.
- People with Anorexia Nervosa, binge/purging type also severely restrict how much food they eat and the types of food they consume, but have also purged their food through self-induced vomiting or misused laxatives/diuretics/enemas within the last three months. They may binge as well.

Bulimia Nervosa is characterized by:

- Recurrent episodes of binge eating (consumption of excessively large amounts of food within a short period of time; lack of control over eating during episode)
- o Recurrent inappropriate compensatory behaviors to prevent weight gain
- Self-evaluation unduly influenced by body shape and weight

Avoidant Restrictive Food Intake Disorder is characterized by:

- Eating disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs and associated with significant weight loss, significant nutritional deficiency, dependence on enteral feeding or supplementation, and/or marked interference with psychosocial functioning
- o No evidence of disturbance in the way one experiences one's body shape or weight

Other Specified or Unspecified Feeding or Eating Disorder is characterized by:

 Eating disorder that causes significant distress or impairment but does not meet full criteria for another disorder

Please note: While there are several other disorders that are classified as Feeding and Eating Disorders in the DSM-5, including Pica, Rumination Disorder and Binge-Eating Disorder, the disorders mentioned above are the most likely to require medical management utilizing the Eating Disorder Clinical Pathway if the child is meeting criteria for admission.

Clinical Management:

Care Plan Goals:

- Medically stabilize patients meeting criteria for inpatient admission due to medical complications of anorexia nervosa or other eating disorders.
- Take a unified, multidisciplinary approach to provide support for immediate physical and psychiatric needs as they are identified.
- o Facilitate communication among team members, the patient, and the family.
- Monitor patient for complications related to malnutrition and refeeding, including, but not limited to, electrolyte derangement, and physiologic instability (orthostasis, arrhythmia, bradycardia, hypotension, hypothermia.)
- Empower and support the patient and family in accessing available resources for ongoing care after hospital discharge

Johns Hopkins All Children's Hospital

Eating Disorder Emergency Center Clinical Pathway

Medical Stabilization for Patients with Suspected or Confirmed Eating Disorders

Emergency Center (EC) Assessment:

- Obtain vital signs, including orthostatic HR & BP and oral temperature
- Obtain height and weight (obtain weight while patient is rear-facing, in gown and undergarments only). Do not discuss weight with patient!
- Obtain labs: CMP, urine pregnancy, Mg, Phos

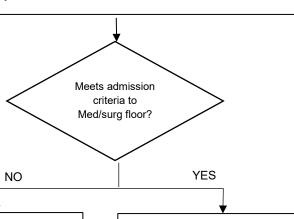
Admission Criteria:

Can include any of the following:

- Weight <75th% Ideal Body Weight (IBW)
 - EC physicians may use calculation method in Appendix A as screening tool to determine if patient meets admission criteria
- Continued weight loss despite intensive outpatient therapy
- · Acute weight decline and refusal of food
- Hypothermia (< 96 F)
- Hypotension (SBP < 90)
- Bradycardia (resting HR <50 bpm while awake and <45 bpm while asleep)
- Orthostatic changes in BP (decrease in SBP of at least 10 mm Hg)
- Orthostatic changes in HR (increase in HR by at least 20 bpm)
- Electrolyte Abnormalities
- Arrythmia

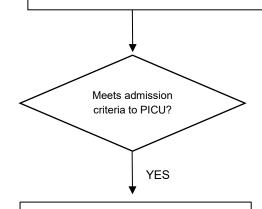
Consider admission to PICU for any of the following:

- Heart rate less than 30 regardless of symptoms
- Heart rate less than 40 with syncope
- Cardiac arrhythmia
- QTc greater than 500ms
- Electrolyte derangements requiring IV replacement that cannot be carried out on the floor or requiring telemetry monitoring



 Refer to SW for assistance with providing appropriate outpatient and community resources for discharge

- Contact Hospitalist
- Place NG tube
- Implement ED Pathway
- Counsel family that JHACH provides medical stabilization and initiation of nutritional resuscitation and is not a licensed eating disorder treatment center



- Contact Intensivist
- Proceed with placement of NG tube if no clinical contraindications
- Implement ED pathway
- Counsel family that JHACH provides medical stabilization and initiation of nutritional resuscitation and is not a licensed eating disorder treatment center

Emergency Center Management

- Presenting symptoms may include restriction of oral intake, purging behaviors, acute weight loss, fear of eating or food refusal, calorie counting, obsession with weight or body image, bradycardia, syncope, amenorrhea, lanugo, excessive exercise, intense fear of weight gain, dehydration, or other eating-related parental concerns.
- When patients present to the EC with a suspected or confirmed eating disorder and may require medical stabilization, obtain history, anthropometrics, vital signs, screening labs, and EKG to determine disposition and need for inpatient admission.
- Orthostatic measurements: HR & BP after 5 minutes of supine rest, then after 3 minutes of standing
- If patient meets any criteria or there is continued suspicion for an eating disorder diagnosis mentioned above but patient remains medically stable for discharge, ensure social work has met with family to provide mental health resources, which may include eating disorder specialists and treatment centers. Additionally, recommend routine PCP visits and referral to JHACH Adolescent Medicine Eating Disorder Clinic.
- If admission is required, NG tube is to be placed prior to transfer to inpatient unit, when possible.
- Admitting physician/team is responsible for introducing the goals and highlighting the care plan with family upon admission. Admitting nurse is responsible for distributing handouts to patient, family, and CPO (see "Inpatient Management").
- Consult EC Social Work. All patients being admitted for eating disorders must also undergo SRA (Suicide Risk Assessment).

Admission Criteria:

Can include any one of the following criteria:

- Weight < 75 percent (%) of Ideal Body Weight (IBW)
 - Emergency room physicians may use calculation method in Appendix A as screening tool to determine if patient meets inpatient criteria.
 - Registered Dietitian (RD) and Hospitalists should use the following formula during their assessment, as supported by medical literature:
 - IBW = 50th percentile BMI for exact age and height at presentation on the CDC BMI-for-age percentiles chart (See Appendix A).
- o Continued weight loss despite intensive outpatient therapy.
- Acute weight decline and refusal of food.
- Hypothermia (< 96 degrees F).
- Hypotension (SBP < 90 mmHg).
- o Bradycardia (resting HR < 50 bpm while awake and < 45 bpm while asleep).
- Orthostatic changes in BP (decrease in SBP of at least 10 mmHg)
- Orthostatic changes in HR (increase in HR by at least 20 bpm)
- Electrolyte abnormalities
- o Arrhythmia.

Johns Hopkins All Children's Hospital

Eating Disorder Inpatient Clinical Pathway

Medical Stabilization for Patients with Suspected or Confirmed Eating Disorders

Med/Surg/PICU Assessment:

- Obtain vital signs, including orthostatic HR & BP and oral temperature
- Obtain height and weight (obtain weight while patient is rear-facing, in gown and undergarments only). Do not discuss weight with patient!
- Obtain labs: CMP, magnesium, phosphorous, thyroid function studies, zinc, vitamin D (250H vitamin D), amylase, serum ferritin, CRP, and lipase.

During Admission: Upon Admission: Monitor for refeeding syndrome: BMP, NG tube will remain in place through duration of Magnesium, Phosphorus daily for at admission - begin on 24/7 continuous feeds (Phase 1) least first 3 days of admission Post-void weight will be obtained daily Start on supplements: multivitamin w/iron, calcium by 7am carbonate, vitamin D3, zinc, thiamin(e)/vitamin B1 Once vital signs are stable (HR >50 Place necessary consults: Nutrition, Social Work, while awake, HR> 45 while asleep, BP Psychology, Child Life, and Case Management normal for age and height) for 24 hrs., Order CPO for 24/7 monitoring vital signs can be spaced to qshift. Patient will move to Phase 2 & 3 of Admitting RN to provide handouts to family, patient, feeding plan at discretion of dietitian and CPO SW to plan care conference within 1-2 If PICU, transfer to med/surge floor when critical weekdays of admission, with additional symptoms resolve conferences as needed SW to coordinate referrals & assessments with appropriate level of care for ongoing ED treatment CM to assist with verifying insurance Is patient medically stable? (Including normal serum chemistries and mental health benefits for at least 24 hrs) CPOs to monitor patient behavior and compliance with ED pathway standards Provide referral to outpatient ED Clinic YES NO Continued monitoring of refeeding syndrome and vital signs Does patient meet Consider additional discharge criteria to home? medications/supplements Continued followed up by all subspecialties originally consulted YES NO

Discharge to Inpatient/Residential Treatment:

- Med: update clinical notes to document medical stability & need for use of NG and CPO
- SW: coordinate with treatment programs and once accepted, notify family and provide contact info
- CM: get safe transport and treatment authorized
- Nursing: complete interfacility transfer form
- NG remains in place for transport if NG is still primary form of nutritional intake

Discharge to PHP/IOP/Outpatient Treatment:

- HR >50 day, >45 at night, no EKG changes, no symptomatic orthostasis, normal temperature (>36C), normal BP
- Patient is consuming minimum amount of nutrition necessary as determined by dietitian & medical team
- Plan of care in place, including appointments made & confirmed with appropriate providers
- If NG tube is no longer in use, remove at time of d/c

Inpatient Management

Patient Care:

- All patients will have a nasogastric (NG) tube placed in the Emergency Center (EC) or immediately upon on admission. The NG tube will stay in place until day of discharge.
- Admitting RN will be responsible for printing and distributing the following five
 (5) handouts once Eating Disorder (ED) Pathway is initiated:
 - For Constant Patient Observer (CPO): <u>Appendix E "Eating Disorder</u>
 Constant Patient Observer Checklist" (2 pages)
 - For patient: "Patient Handout" (<u>Appendix F for English</u>, <u>Appendix G for Spanish</u>)
 - For parent/caregiver: "Caregiver Handout" and "Tips for Caregivers"
 (Appendix F for English, Appendix G for Spanish)
 - Please also provide an <u>Outpatient Eating Disorder Clinic</u> handout.
- Orthostatic vital signs will be obtained on admission and qAM until normalized.
- Orthostatic measurements: HR & BP after 5 minutes of supine rest, then after 3 minutes of standing
- Initially, vital signs will be monitored per unit protocol. Only oral temperatures will be utilized.
- Once vital signs are stable (HR >50 while awake, HR> 45 while asleep, BP normal for age and height) for 24 hours, if the patient is not otherwise eligible for discharge, vital signs can be monitored q shift. Post-void weight will be obtained daily by 7am, and patient will be rear-facing and in a hospital gown and undergarments only while being weighed. Weight will never be discussed with patient.
- Constant Patient Observer (CPO) will be ordered 24 hrs/day.
- Patient is not permitted to exercise throughout admission. This includes but is not limited to pacing, repetitive or frequent movements around the room, repetitive contracting and relaxing of muscles (i.e., sit ups, crunches, new TikTok fads, leg lifts, calf raises), and standing activity center activities (i.e., pool, walkway floor activity, stair use). The patient may be in a chair, on the couch, or in bed.
- Patient is able to leave room escorted by CPO. Patient must be in a
 wheelchair for the duration of the excursion. Please notify RN or Charge RN
 before leaving the unit. Excursions may not interfere with meals or snack
 times
 - Patient is not permitted to visit the café or cafeteria.
- Patient cannot use the bathroom for 60 minutes following completion of meals.
- Patient is permitted one shower per day.
- Thermostat will be set in the middle (12 o'clock position) by the CPO or RN and is not to be changed by the patient or family.
- Patient will not be allowed to chew gum.

Consults & Referrals:

- Nutrition, Social Work, Psychology, Child Life, and Case Management should be consulted upon admission.
- A referral to the Outpatient Interdisciplinary Eating Disorder Clinic should be ordered upon admission due to wait times to get into clinic.
 - Order Outpatient Referral to Adolescent Medicine and type "Eating Disorder Clinic" in the comments.
 - Goal is for patient to be followed in Eating Disorder Clinic during and after any intensive therapy program they enter upon discharge.
- Psychiatry consult should be considered if assistance with psychotropic medication management is needed.
- Academic Services consult may be considered depending on length of stay and family interest.

o Diet:

Upon admission:

- NG tube is placed upon admission and will remain in place until discharge. If NG tube becomes dislodged for any reason, NG tube will be replaced in a timely manner. Patient to start on continuous NG feeds per Feeding Plan outlined below. The dietitian will determine the appropriate time to start the meal plan once they have assessed the patient.
- Excluding formula and nutritional supplements, an oral fluid restriction of 1,000 mL/day will be in place during the entire admission. Oral fluid restriction does not include fluids sent by dietitian on meal plan trays. No caffeinated beverages are permitted.
- Patient to have regular diet for age ordered upon admission. Patient can consume food in addition to enteral feeds.
- Nursing to cover enteral pump and formula with a pillowcase to avoid patient fixating on numbers/attempting to calorie count. Formula in cartons or cans will not be brought into the room by nursing to also avoid fixation on numbers/attempts to calorie count.

When meal plan is initiated:

- Food from home is allowed but does not count towards the meal plan established by the dietitian. The food is counted in addition to the meal plan.
- Accommodations for medically approved food allergies, religious exemptions, and vegetarian preferences will be made at the dietitian's or medical team's discretion.
- Each meal or snack must be completed within the allotted 30 minutes timeframe.
- Meals will take place in the patient's room, in a stand-alone chair, supervised by medical staff. Family members can be present, but will be asked to leave if family is not able to display supportive behaviors during meals. TV use is allowed during meals for distraction unless patient is watching triggering content.

- Food labels (on meal trays or on formula) should not go into the patient room to ensure patient is not fixating on numbers/calories.
- If patient is found throwing away food or manipulating enteral feeds, the dietitian will adjust the nutrition plan accordingly to ensure nutrition goals are met.
- Patient may be allowed to wear personal clothing unless concerning behaviors occur, at which time the medical team may modify the arrangements and transition patient into a hospital gown.
- Patient will not be allowed to chew gum.

Feeding Plan:

The feeding plan will be implemented in the following order but may be modified at the discretion of the dietitian:

Phase 1:

- Continuous NG feeds 24 hrs/day will be started upon admission based on age:
 - Patients ages 8-13 years old: Pediasure 1.5 at 42 ml/hr x 24 hours.
 - Patients ages 14 and older: Vital 1.5 at 50 ml/ hr x 24 hours.
- The RD will see the patient within 24 hours of admission and calculate the patient's goal calorie intake/enteral rate.
- Continuous NG feeds will be advanced by 200 kcals (or 6 ml/hr) every day until goal calorie intake is achieved or per the dietitian recommendations.
- Patient will be on a regular diet for age with a 1000 ml fluid restriction and can order food by mouth as desired.

Phase 2:

- Once max calories are achieved via NG supplementation (or earlier at the discretion of the dietitian), the RD will initiate an oral feeding plan with three meals and 1-3 snacks per day. The menu will be pre-selected by the RD and sent to the kitchen the day prior. Feeds increased at the following rate, pending acceptance of food PO.
 - 1st day: 50% kcals from PO meal plan, + 50% kcal via NG at night.
 - 2nd day: 75% kcals from PO meal plan, + 25% kcal via NG at night.
 - 3rd day: 100% kcals from PO meal plan + 0% kcal via NG at night.
- If patient refuses any portion of a meal or snack, or does not complete 100% within 30 minutes, a full kcal equivalent of formula will be offered PO. If refused PO, it will be given via NG.

Phase 3:

- 100% of nutrition needs are met via PO meal plan, with no scheduled NG feeds, unless patient refuses any portion of a meal or snack.
- NG tube will stay in place until day of discharge.

Laboratory Evaluation:

- On admission: CMP, magnesium, phosphorous, thyroid function studies, zinc, vitamin D (25OH vitamin D), amylase, serum ferritin, CRP and lipase.
 - If patient has had zinc, ferritin, vitamin D, thyroid function labs within the last 3 months, repeat labs may not be necessary.
- Consider serum B12 and methylmalonic acid (serum) if the patient is on a vegan diet.
- Consider urine pregnancy screening on admission, if not already performed.
- BMP, Magnesium, and Phosphorous levels will be monitored upon admission to assess for refeeding syndrome.
- Recommend checking BMP, Magnesium, Phosphorus daily for the first 3 days of admission.
 - If labs remain stable after first 3 days, check labs again on day 7 of admission. If labs remain normal on day 7 of admission, routine labs are not necessary unless clinically indicated. If labs remain abnormal, continue checking at least daily until normalized.
 - Additional labs may be drawn at the discretion of the accepting treatment facility.
- The major manifestations of refeeding syndrome include delirium, chest pain, and heart failure that is associated with hypophosphatemia and depletion of potassium and magnesium
- Consider checking post-prandial glucose in patients with "brain fog" or low-normal fasting glucose, especially during the first week of hospitalization. Post-prandial hypoglycemia is common in eating disorder patients and may be asymptomatic or present with atypical symptoms, such as isolated "brain fog" without associated shakiness or sweating. Patients on bolus feeds or eating meals, especially early in their nutritional rehabilitation, may have post-prandial hypoglycemia despite normal fasting glucose.

Medications:

The following supplements will be started for all patients upon admission:

- Daily oral pediatric multivitamin with iron (Cerovite Jr or equivalent)
- Calcium Carbonate: 500 mg PO BID. Consider TID if not consuming dairy.
- Vitamin D3 (Cholecalciferol): If 25OH vitamin D <30 ng/dL: 2000 IU daily x 6-8 weeks.
- Zinc: if deficient, provide 15 mg (age 4-8), 30 mg (age 9-13), or 45 mg (adolescents and adults) elemental zinc PO q day.
- Thiamin(e)/Vitamin B1: 50 mg/day (children under 13) or 100 mg/day (13 and older).

Consider the following depending on the clinical scenario:

- Iron: if serum ferritin <12 ng/mL, provide 3-6 mg ferrous sulfate/kg/day for children, 325 mg/day for adults.
- Vitamin B12 (cyanocobalamin): if MMA >0.4 mmol/L, 250 mcg/day x 8 weeks.
- Prophylactic PhosNaK (phosphorous-sodium-potassium) 250 mg PO TID should be prescribed if serum phosphorous level is < 3.0 mg/dL or is trending downward, OR if serum potassium level is < 3.4 mg/dL or trending downward.
- Magnesium oxide 400mg BID or TID should be prescribed if serum magnesium level is < 1.5mg/dL or trending downward. Monitor for diarrhea.
- Once the patient is on full enteral feeds, consider Miralax 17g PO q HS if no bowel movement > 3 days.

o IV Fluids:

- Fluid requirements will generally be met by oral/enteral nutrition plan recommended by dietitian.
- IV Fluids are not routinely recommended, but may be provided at the discretion of the physician based on the clinical status of the patient, taking into consideration the hydration status, electrolytes, and cardiac status of the patient.

Patient Status Recommendations:

 Patients admitted for medical stabilization and nutritional resuscitation for suspected or confirmed eating disorder should be admitted to inpatient status.

Team Communication:

- The inpatient social worker is responsible for coordinating a family conference with the multidisciplinary team within 1-2 business days of admission. The goal of this meeting is to review the patient's diagnosis, provide education to the family, set expectations, and review the plan of care.
 The inpatient social worker will coordinate referrals to eating disorder treatment facilities for the corresponding level of care.
- The inpatient case manager is responsible for verifying insurance and mental health benefits, and educating the family of their plan benefits. The inpatient case manager will secure the authorization for the safe authorized mode of transportation for transfers to an accepting treatment facility. Review of discharge home prescriptions if applicable.
- A second family conference should be considered once transition plan recommendations are available from members of the multidisciplinary team.

Discharge

Discharge Criteria

Discharge to Inpatient or Residential:

Criteria for transfers to higher levels of care or treatment facilities may differ depending on facility requirements.

- Patients on an NG tube identified for transfer from JHACH to an ED treatment facility will transfer via safe authorized mode of transportation to the accepting treatment facility.
- Social Work: Coordinate referrals to appropriate level of care. Assist nursing
 with necessary information on interfacility form for transfer. Notify parent of
 the accepting ED treatment facility and provide contact information.
 Coordinate with case management to secure the safe authorized mode of
 transportation for transfers to an accepting treatment facility.
- Case Management: Obtain insurance authorizations for transportation for transfers for appropriate level of care. Coordinate with social work to secure the safe authorized mode of transportation for transfers to an accepting treatment facility. Review of discharge home prescriptions if applicable.
- Medical: Update clinical notes to accurately reflect use of NG tube and CPO as part of clinical pathway. Document medical stability once clinical criteria for medical stability have been met.
- Nursing: Ensure Interfacility transfer form has been completed, Review discharge AVS. NG tube remains in place for transfer if majority of nutrition is received via NG tube.

Discharge Criteria for discharge to home:

- Medical: Normal serum chemistries for at least 24 hours. Medical instability
 has resolved, at discretion of medical team: HR >50 during the day, >45 at
 night, no EKG changes, normal temperature (>36C) taken orally (not axillary),
 normal blood pressure for age, resolution of symptomatic orthostasis
 (decrease in BP no greater than 10 mmHg diastolic or 20 mmHg systolic and
 increase in HR no more than 20 bpm, measured after 5 minutes supine rest
 and then again after 3 minutes standing)
- If the patient has a recent history of admission in the last 30 days for the same issue, discharge is at the discretion of the physician. Requirements for next levels of care (e.g., IOP or PHP programs) may also inform decisions regarding discharge readiness.
- Social Work: Plan of care in place, including appointments made and confirmed with appropriate providers (psychology, nutrition, PCP, etc.).
- A warm handoff from inpatient to outpatient providers is recommended, when feasible, to facilitate continuity of care.
- Patient does not have to complete all 3 Phases of the Feeding Plan to be eligible for discharge. Patient does not have to be taking all PO feeds to be eligible for discharge.

Documentation Reminders

Documentation Recommendations

- It is important to document the underlying psychiatric diagnosis. Refer to the psychology notes for terminology. If psychology has not yet seen the patient, using terms like "suspected," "probably," "presumed," or "likely" is appropriate.
- Review "Background" section above for assistance.
 - Anorexia nervosa, restricting type, F50.01
 - Anorexia nervosa, binge eating/purging type, F50.02
 - Bulimia nervosa, F50.2
 - Binge eating disorder, F50.81
 - Avoidant-restrictive food intake disorder (ARFID), F50.82
 - Other specified eating disorder, F50.89
 - Unspecified eating disorder, F50.9
- It is also important to document the patient's BMI and degree of malnutrition. Refer to the nutrition notes for guidance.
 - Mild malnutrition, E44.1
 - Moderate malnutrition, E44.0
 - Severe malnutrition, E43.0
- It is important to document any complications of the patient's eating disorder, such as bradycardia, orthostatic hypotension, orthostatic tachycardia, electrolyte abnormalities (hypokalemia, hypophosphatemia), refeeding syndrome, lanugo, hair loss, amenorrhea, etc.
- It is important to document any mental health comorbidities that could be contributing to the patient's disordered eating, avoidant behaviors, or oral aversion.

Outcome Measures

Frequency of collection of labs: BMP, Mg, Phos Frequency of below-normal phosphorus levels

Frequency of below-normal phosphorus levels resulting in supplementation

Frequency of documented diagnosis of refeeding syndrome

References

- 1. Academy of Nutrition and Dietetics (Pediatric Nutrition Practice Group). Review of Common Micronutrient Deficiencies and Supplementation Recommendations in Patients with Eating Disorders. PNPG Building Blocks for Life 2019;42(1);9-11.
- 2. Agostino H, et al. Shifting paradigms: continuous nasogastric feeding with high caloric intakes in anorexia nervosa. Journal of Adolescent Health 2013;53;590
- 3. American Academy of Pediatrics, Committee on Adolescence. Identifying and treating eating disorders. Pediatrics 2003;111;204
- 4. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (5th ed.). 2013; Washington, DC.
- 5. Baran SA, et al. Low discharge weight and outcome in anorexia nervosa. Am J Psychiatry 1995;152(7);1070
- Brynes N, Tarchichi T, McCormick AA, Downey A. Restrictive Eating Disorders: Accelerating Treatment Outcomes in the Medical Hospital. Hospital Pediatrics. 2021;11(7):751-759. doi:10.1542/hpeds.2020-005389
- 7. Da Silva JS v., Seres DS, Sabino K, et al. ASPEN Consensus Recommendations for Refeeding Syndrome. Nutrition in Clinical Practice. 2020;35(2):178-195. doi:10.1002/ncp.10474
- 8. Ghaddar R, Chartrand J, Benomar A, et al. Excessive laboratory monitoring to prevent adolescent's refeeding syndrome: opportunities for enhancement. Eating and Weight Disorders Studies on Anorexia, Bulimia and Obesity. 2020;25(4):1021-1027. doi:10.1007/s40519-019-00723-7
- 9. Garber AK, et al. A prospective examination of weight gain in hospitalized adolescents with anorexia nervosa on a recommended refeeding protocol. Journal of Adolescent Health 2012:50:24
- 10. Goldstein MA, et al. Eating Disorders. Pediatrics in Review 2011;32;508
- 11. Hornberger LL, Lane MA, Hornberger LL, et al. Identification and Management of Eating Disorders in Children and Adolescents. Pediatrics. 2021;147(1). doi:10.1542/peds.2020-040279
- 12. LeGrange D, et al. (2012). Calculation of Expected Body Weight in Adolescents With Eating Disorders. Pediatrics 2012;129(2);1
- 13. Proulx-Cabana S, Metras ME, Taddeo D, Jamoulle O, Frappier JY, Stheneur C. To Improve the Initial Inpatient Management of Adolescents Admitted with Severe Anorexia Nervosa: A Narrative Review and a Convenient Protocol. Nutrients. 2022;14(1):229. doi:10.3390/nu14010229
- Ridout KK, Kole J, Fitzgerald KL, Ridout SJ, Donaldson AA, Alverson B. Daily Laboratory Monitoring is of Poor Health Care Value in Adolescents Acutely Hospitalized for Eating Disorders. Journal of Adolescent Health. 2016;59(1):104-109. doi:10.1016/j.jadohealth.2016.03.015
- 15. Rosen DS, et al. Identification and Management of Eating Disorders in Children and Adolescents. Pediatrics 2010;126;1240
- Sachs K v., Harnke B, Mehler PS, Krantz MJ. Cardiovascular complications of anorexia nervosa: A systematic review. International Journal of Eating Disorders. 2016;49(3):238-248. doi:10.1002/eat.22481
- 17. Smith K, Lesser J, Brandenburg B, et al. Outcomes of an inpatient refeeding protocol in youth with Anorexia Nervosa and atypical Anorexia Nervosa at Children's Hospitals and Clinics of Minnesota. Journal of Eating Disorders. 2016;4(1):35. doi:10.1186/s40337-016-0124-0

Clinical Pathway Team <u>Eating Disorder Clinical Pathway</u> *Johns Hopkins All Children's Hospital*

Owner(s): Kimberly Collins, MD and Aaron Samide, MD

Also Reviewed by:

Specialists: Marissa Feldman, PhD, Susan Stroup, LCSW, Anna Metz, LCSW, Brenna

Denhardt, RD

Hospitalists: Paola Dees, MD Intensive Care: Nathan Dean, MD

Emergency Center: Jennifer Stritar, BSN, Wassam Rahman, MD

Resident Physicians: Kenneth Hearn, MD, Sandra Al Tamimi, MD, Emily Zander, MD Nursing: Carrie Kleinmeier, MSN, Aimee Dvoracsek, BSN, Julie Pham, BSN, MBA

Johns Hopkins Children's Center Team:

Others: Jasmine Reese, MD, Sarah Sobalvarro, PhD

Clinical Pathway Management Team: Joseph Perno, MD; Courtney Titus, PA-C

Date Approved by JHACH Clinical Practice Council: 10/19/23

Date Available on Webpage: 11/17/22

Last Revised: 3/13/23

Disclaimer

Clinical Pathways are intended to assist physicians, physician assistants, nurse practitioners and other health care providers in clinical decision-making by describing a range of generally acceptable approaches for the diagnosis, management, or prevention of specific diseases or conditions. The ultimate judgment regarding care of a particular patient must be made by the physician in light of the individual circumstances presented by the patient.

The information and guidelines are provided "AS IS" without warranty, express or implied, and Johns Hopkins All Children's Hospital, Inc. hereby excludes all implied warranties of merchantability and fitness for a particular use or purpose with respect to the information. Johns Hopkins All Children's Hospital, Inc. shall not be liable for direct, indirect, special, incidental or consequential damages related to the user's decision to use the information contained herein.

Appendix A: Calculating Ideal Body Weight (IBW) and Percent of IBW

- IBW (ideal body weight) is the patient's weight if their BMI were at the 50th percentile.
- The goal is generally for eating disorder patients to maintain at least 90-110% IBW.

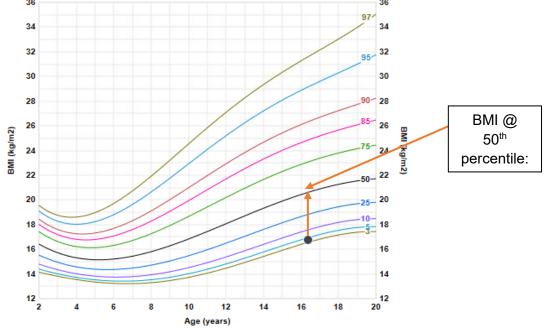
Steps to Calculate IBW (with example):

Step 1: Obtain height (m) and weight (kg).

Example: Height: 1.571 m Weight: 41.3 kg

<u>Step 2:</u> Look at BMI growth chart (CDC 2-20 years). Find what BMI would be at 50th percentile (can also find BMI at 50th percentile using https://peditools.org/growthpedi/):





<u>Step 3:</u> To find patient's IBW, use the following equation. Plug in the BMI from Step 2 and the patient's height, and then solve for x (weight in kg).

$$\textit{BMI} @ 50th \ percentile = \frac{\textit{weight} \ (\textit{kg})}{\textit{height} \ (\textit{m}^2)}$$

$$20.6 \ kg/m^2 = \frac{x}{1.571^2}$$

$$x = 50.8 \, kg$$

Step 4: Determine patients' percent of ideal body weight (% IBW) using the following equation:

$$\% \, IBW = \frac{actual \, weight}{ideal \, weight} \times 100$$

$$81\% \, IBW = \frac{41.3 \, kg}{50.8 \, kg} \times 100$$

Patient is 81% ideal body weight

Appendix B: Eating Disorder Handout for Caregivers

Goals for This Hospital Stay:

- Your child has been admitted to Johns Hopkins All Children's Hospital (JHACH) under the Eating Disorder Pathway. During this stay, your child will be assessed by many team members, including doctors, psychologists, social workers, and dietitians.
- JHACH is a **medical** facility, not a behavioral health care facility or eating disorder treatment facility. The goal during this stay is to medically stabilize your child so that they are safe to start treatment for their eating disorder after discharge from this hospital.
- We will monitor vital signs, weight, and labs and provide nutrition based on your child's unique needs. As we do all of these things, we will also be working with your child and family to identify the best treatment after discharge and help get you there.

What to Expect in the Hospital:

- You will work closely with a dietitian to address your child's nutrition needs. Medical allergies and religious preferences will be taken into account.
- Your child's weight and plan of care will be discussed with you, but weights and calories should **not** be discussed or shared in front of your child. These topics are very stressful and triggering to patients with eating disorders. Discussing them could be harmful to your child's safety and recovery.
- A team member will be present to monitor your child throughout this hospital stay. This includes, but is not limited to, during all meals and snacks, bathroom time, shower time, and when leaving the room in a wheelchair.
- Your child may try to restrict or burn calories in ways beyond just limiting food. These can include keeping the room cold to cause shivering; taking cold showers; exercising secretly in the bathroom, shower, or bed; fidgeting; pacing; drinking lots of water; or using laxatives. None of these will be allowed in the hospital.
- It is recommended that your child **not** use electronics. Phones, laptops, gaming devices with internet access, etc. can be and have been used to count calories and learn ways to burn calories without getting caught. Social media can be very toxic to the health of patients with eating disorders. The smart TV in the room can be used for distraction during meals if helpful. If your child is using electronics in a way that is harmful to their progress, the medical team will make a formal recommendation against the use of electronics.
- Eating disorders are often linked to suicidal thoughts or thoughts of self-harm. Concerns about these matters should be addressed openly and honestly.
- Your child's safety and medical stability are our priorities. Please be aware that any statements or behaviors suggesting self-harm or attempts to "run away" are taken seriously and may involve further restrictions.

Planning for Next Steps:

- The team will organize a care conference within 1-2 business days of your arrival. As a group, we will discuss your child's diagnosis and plan of care with you. This meeting typically only includes parents. The topics discussed in the meeting can be triggering for your child.

Page 1 of 2

- It is very important for you to be involved in the planning of your child's future care. Please contact your insurance company after the first care conference to discuss the team's recommendations and make them aware of your child's diagnosis and medical needs. If appropriate, request an insurance case manager from your primary insurance to aid you in this process.
- The next steps after leaving the hospital will depend on your child's unique needs and may include intensive outpatient or even residential treatment for the eating disorder. We will work as a team to figure out the most appropriate and safest route for your child.
- A second, or follow-up, care conference may be held as needed.
- Discharge from the hospital will be considered when a) your child is medically stable and b) a safe plan for their treatment outside of the hospital is in place.

Tips for Caregivers and Supporters:

- Recovery from an eating disorder is a long-term process. There is no quick fix. However, recovery **is** possible, and it is very important to get help as soon as possible.
- Rules and restrictions while your child is in the hospital are not punishments; they are needed for your child's safety.
- Eating disorders are not specific to any race, gender, ethnicity, body type, sexual orientation, or socioeconomic status. They can impact anyone. Do not blame yourself; it is not something you did wrong.
- Remember that a child with an eating disorder is not purposely choosing to do or say harmful or hurtful things. Be positive, and try not to take these things personally. The illness, or "eating disorder brain," is affecting the decisions your child makes.
- Be firm and consistent with your child. Avoid power struggles. Do not try to trick, bribe, or force your child to eat.
- Be non-judgmental. Focus on feelings, not weight or food. Obsession with numbers, such as weights and calories, is a dangerous part of eating disorders.
- Many families find it helpful to join support groups for eating disorders. These groups can help you learn about others' experiences with their children's eating disorders and give you a safe space to express yourself and share your own.
- Take care of your own physical, emotional, and spiritual needs. Your child is being kept safe while in the hospital. It is okay to take breaks away from their bedside to meet your own personal needs.

<u>Appendix C: Handout for Patient - Expectations for Patients Admitted for Medical</u> <u>Stabilization of Eating Disorder</u>

- An NG tube is placed through your nose to your stomach in order to safely meet your nutrition needs. This will remain in place from admission to discharge. If your tube comes out during your stay, the nurse will replace it.
- A member of your care team will be with you at all times. This observation includes but is not limited to bathroom use, shower use, during mealtimes, and also when outside the room.
- To ensure your safety, the expectation is to stay in your bed, on your couch, or in a chair while in your room. If there is concern for more frequent movement, your care team will provide reminders.
- Showers will be limited to once daily with warm water only.
- The room thermostat will remain in the 12 o'clock position to maintain a consistent room environment. Please notify your nurse if you suspect your thermostat is malfunctioning.
- Exercise is not allowed during your stay. This includes taking walks, pacing, repetitive movements, etc.
- Gum will not be allowed during your stay.
- For any excursions outside your room, a wheelchair is to be supplied for you to remain in for the entirety of the trip.
- Every morning, after you have urinated, your weight will be measured in a gown and underwear only while you face backwards. Blind weights are used to reduce eating disorder triggers.
- Please don't flush the toilet; your nurse will need to measure the urine and stool after each bathroom use.
- Bathroom use will be allowed 1 hour after completion of meals.
- Once a meal plan is started, meals and snacks will be completed in a chair (not in bed or couch) within a 30-minute timeframe. All napkins must be returned on your tray. In case of concern for hiding food, a gown will be worn during meal and snack times.
- If you are unable to eat and drink all items on your tray (even if only a few bites), the meal or snack's full nutritional value will be offered the form of oral supplementation. If oral supplementation is declined, nutrition will be provided via your NG tube.
- Your dietitian will work with you and your family to develop a meal plan to meet your nutritional needs. Medically diagnosed allergies and religious exemptions will be taken into account.
- We prioritize your safety. Any comments made that raise concern for your safety and wellbeing will be taken seriously.

Page 1 of 1

Appendix D: Task Description for Constant Patient Observer (CPO)

- Obtain start of shift report from CPO and bedside RN. If no report available, check in with Charge RN
- Check NG tube connections for leaks or breaks when vitals are obtained
- Ensure enteral pump & formula remain covered at all times.
- Blind weights should be taken by 7am. Patient must void prior to weight being taken, must be in gown. Notify bedside RN or Charge RN if patient does not void, refuses gown or refuses weight by 7am
- Eyes and attention must be on patient at all times. Your view of the patient must be unobstructed. You should not have nor be using, your personal phone, should not be using the room computer for personal use, and are not permitted the use of headphones. Reading a book is not maintaining eyes and attention on the patient at all times.
- If you are feeling sleepy or need a immediate break, please call the bedside RN or Charge RN as soon as possible.
- Please do not discuss weight, foods, calories or eating disorder treatment with patient.
- Please notify bedside RN if you are concerned patient is using a phone or electronic inappropriately. Examples for concerning behaviors include: counting calories, inappropriate social media access, concerning content or videos related to eating, conversations regarding self-harm, elopement (running away), or any other concerning behaviors.
 - Patient can have a phone until medical team places a formal recommendation for no phone/electronic use.
 - o A parent can choose to limit their child's phone/electronic use at any time.
- During meals:
 - Please check tray to ensure no items on tray include a nutritional label. If identified, do not provide tray to patient, notify bedside RN or Charge RN immediately.
 - Patient must be in a stand-alone chair (not in bed or couch) for duration of meal and snacks. Family members can be present, but will be asked to leave if family is not able to display supportive behaviors during meals. TV use is allowed during meals for distraction unless patient is watching triggering content.
 - o Meals and snacks must be consumed within 30-minute timeframe
 - Patient is expected to consume 100% of meal and snack, including small bites remaining, condiments ordered on the tray, and all liquids.
 - o Patient should not have any blankets or outerwear during meals.
 - No additional belongings are to be with patient during meals
 - Napkins must be turned in with tray and checked
 - Cups, utensils must be confirmed and turned in with tray
 - Please confirm clothing is not used to hide foods. Notify bedside or Charge RN if suspect food is being hidden
 - Patient cannot use the bathroom for 60 minutes following completion of meals
 - Please report any concerns for purging to bedside RN or Charge RN as soon as possible
- Patient is not permitted to chew gum.
- TV can be utilized by patients
 - Should concerning content be viewed, please notify bedside RN or Charge RN
- Patient is able to leave room escorted by CPO. Patient must be in a wheelchair for the duration of the excursion. Please notify RN or Charge RN before leaving the unit.
 Excursions may not interfere with meals or snack times
 - o Patient is not permitted to visit the café o cafeteria.

- The temperature in the patient's room is to remain in the midpoint position. If there are concerns from patient or family as to the temperature in the room, notify bedside RN/ Charge RN and Hospitalist team.
- Patient is not permitted to exercise throughout admission. This includes, but is not limited to, pacing; repetitive or frequent movements around the room; repetitive contracting and relaxing of muscles (i.e., sit ups, crunches, new tiktok fads, leg lifts, calf raises); and standing activity center activities (i.e., pool, walkway floor activity, stair use)

Appendix E: Printable Handout for Constant Patient Observer (CPO) (2 pages)

Eating Disorder Constant Patient Observer	₹
Checklist	
Obtain start of shift report from CPO and bedside RN. If no report available, check in with Charge RN	
Check NG tube connections for kinks, leaks or breaks when vitals are obtained	
Ensure feeding pump and formula remain covered at all times.	
Blind weights should be taken by 7am. Patient must void prior to weight being taken, must be only in gown and undergarments. Notify bedside RN or Charge RN if patient does not void, refuses to weigh, or refuses gown by 7am	
Measure orthostatics with AM vital signs: -Have patient lay down for 5 minutes. Take a heart rate & blood pressure. -Have patient stand for 3 minutes. Take another heart rate & blood pressure.	
During Meals & Snacks:	
Please check tray to ensure no items delivered on tray include a nutritional label. If identified, do not provide tray to patient, notify bedside RN or Charge RN immediately.	
Patient must be in a stand-alone chair (not in bed or couch) for duration of meal and snacks. Family members can be present, but will be asked to leave if family is not able to display supportive behaviors during meals. TV use is allowed during meals for distraction unless patient is watching triggering content.	
Meals and snacks must be consumed within 30 minute timeframe • Patient is expected to consume 100% of meal and snack, including small bites remaining, condiments ordered on the tray, and all liquids.	
 Patient should not have any blankets or outerwear during meals. No additional belongings are to be with patient during meals Napkins must be turned in with tray and checked Cups, utensils must be confirmed and turned in with tray Please confirm clothing and personal items are not used to hide foods. Notify bedside or Charge RN immediately if suspect food is being hidden 	
Patient cannot use the bathroom for 60 minutes following completion of meals Please report any concerns for purging to bedside RN or Charge RN as soon as possible Please ass Page 2 for additional details	

CPO Guide

- Eyes and attention must be on patient at all times. Your view of the patient must be
 unobstructed. You should neither have nor be using your personal phone, should not be
 using the room computer for personal use, and are not permitted the use of
 headphones. Reading a book is also not permitted, as you would not be maintaining
 eyes and attention on the patient at all times.
- If you are feeling sleepy or need an immediate break, please call the bedside RN or Charge RN as soon as possible.
- Please do not discuss weight, foods, calories or eating disorder treatment with patient.
 Do not make comments about the food on their tray, serving sizes, or how much they ate.
- Please notify bedside RN if patient is counting calories; having inappropriate social media access; having conversations regarding self-harm or elopement (running away); or showing any other concerning behaviors.
- Patient can have their cell phone/electronics unless there are concerns for inappropriate use of phone/electronics.
- Patient is not permitted to chew gum.
- TV can be utilized by patients, but if concerning content is being viewed, please notify bedside RN or Charge RN
- Patient is able to leave room escorted by CPO. Patient must be in a wheelchair for the duration of the excursion. Please notify RN or Charge RN before leaving the unit. Excursions may not interfere with meals or snack times
 - o Patient is not permitted to visit the café or cafeteria.
- The temperature in the patient's room is to remain in the midpoint ("12 o'clock") position. If there are concerns from patient or family about the temperature in the room, notify bedside RN / Charge RN and Hospitalist team.
- Patient is not permitted to exercise throughout admission. This includes, but is not limited to, pacing; repetitive or frequent movements around the room; repetitive contracting and relaxing of muscles (i.e., sit ups, crunches, new TikTok fads, leg lifts, calf raises); or standing activity center activities (i.e., pool, walkway floor activity, stair use)

Please report any additional concerns to bedside RN or charge RN.

Appendix F:

Printable Handouts for Patient & Family (English)

Please print the next 3 pages and distribute upon admission as follows:

To Patient: "Patient Handout"

<u>To Parent/Caregiver:</u> "Caregiver Handout" **and** "Tips for Caregivers"

Patient Handout

Initiation of Eating Disorder Clinical Pathway

Expectations for Patients Admitted for Medical Stabilization of an Eating Disorder

- An NG tube is placed through your nose to your stomach in order to safely meet your nutrition needs. This will remain in place from admission to discharge. If your tube comes out during your stay, the nurse will replace it.
- A member of your care team will be with you at all times. This observation includes but is not limited to bathroom use, shower use, during mealtimes, and also when outside the room.
- To ensure your safety, the expectation is to stay in your bed, on your couch, or in a chair while in your room. If there is concern for more frequent movement your care team will supply reminders.
- Showers will be limited to once daily with warm water only.
- The room thermostat will remain in the 12 o'clock position to supply a consistent room environment. Please notify your nurse if you suspect your thermostat is malfunctioning.
- Exercise is not allowed during your stay. This includes taking walks, pacing, repetitive movements, etc.
- Gum will not be allowed during your stay.
- For any excursions outside your room, a wheelchair is to be supplied for you to remain in for the entirety of the trip.
- Every morning, after you have voided, your weight will be measured in a gown and underwear only, facing backwards. Blind weights are used to reduce eating disorder triggers.
- Please don't flush the toilet; your nurse will need to measure the urine and stool after each bathroom use.
- Bathroom use will be allowed 1 hour after completion of meals.
- Once a meal plan is started, meals and snacks will be completed in a chair (not in bed or couch) within a 30-minute timeframe. All napkins must be returned on your tray. In case of concern for hiding food, a gown will be worn during meal and snack times.
- If you are unable to eat and drink all items on your tray (even if only a few bites), the meal or snack's full nutritional value will be offered the form of oral supplementation. If oral supplementation is declined, nutrition will be provided via your NG tube.
- Your dietitian will work with you and your family to develop a meal plan to meet your nutritional needs. Medically diagnosed allergies and religious exemptions will be taken into account.
- We prioritize your safety. Any comments made that raise concern for your safety and wellbeing will be taken seriously.

 JOHNS HOPKINS

All Children's Hospital

Goals for This Hospital Stay

Your child has been admitted to Johns Hopkins All Children's Hospital (JHACH) under the Eating Disorder Pathway. During this stay, your child will be assessed by many team members, including doctors, psychologists, social workers, and dietitians.

JHACH is a **medical** facility, not a behavioral health care facility or eating disorder treatment facility. The goal during this stay is to medically stabilize your child so that they are safe to start treatment for their eating disorder after discharge from this hospital.

We will monitor vital signs, weight, and labs and provide nutrition based on your child's unique needs. As we do all of these things, we will also be working with your child and family to identify the best treatment after discharge and help get you there.

JOHNS HOPKINS All Children's Hospital

Caregiver Handout

Initiation of Eating Disorder Clinical Pathway

What to Expect in the Hospital

- You will work closely with a dietitian to address your child's nutrition needs. Medical allergies and religious preferences will be honored. Your child's weight and plan of care will be discussed with you. Weights and calories should **not** be discussed or shared in front of your child. These topics are very stressful and triggering. Discussing them could be harmful to your child's safety and recovery.
- A team member will be present to monitor your child throughout this hospital stay. This includes (but not limited to) during all meals and snacks, bathroom time, shower time, and when leaving the room in a wheelchair.
- Your child may try to restrict or burn calories in ways beyond just limiting food. These can include keeping the room cold to cause shivering, taking cold showers, exercising secretly in the bathroom, shower, or bed, fidgeting, pacing, drinking lots of water, and using laxatives. None of these will be allowed in the hospital.
- It is recommended that your child **not** use electronics. Phones, laptops, gaming devices with internet access, etc. can be and have been used to count calories and learn ways to burn calories without getting caught. Social media can be very toxic to the health of patients with eating disorders. The smart TV in the room can be used for distraction during meals if helpful. If your child is using electronics in a way that is harmful to their progress, the medical team will make a formal recommendation against the use of electronics.
- Eating disorders are often linked to suicidal thoughts or thoughts of self-harm. Concerns about these matters should be addressed openly and honestly.
- Your child's safety and medical stability are our priorities. Please be aware that any statements or behaviors suggesting self-harm or attempts to "run away" are taken seriously and may involve further restrictions.

Planning for Next Steps

- The team will organize a care conference within 1-2 business days of your arrival.
 As a group, we will discuss your child's diagnosis and plan of care with you. This meeting typically only includes parents. The topics discussed in the meeting can be triggering for your child. A second, or follow-up, care conference may be held as needed.
- It is very important for you to be involved in the planning of your child's future care. Please contact your insurance company after the first care conference to discuss the team's recommendations and make them aware of your child's diagnosis and medical needs. If appropriate, request an insurance case manager from your primary insurance to aid you in this process.
- The next steps after leaving the hospital will depend on your child's unique needs and may include intensive outpatient or even residential treatment for the eating disorder. We will work as a team to figure out the most appropriate and safest route for your child.
- Discharge from the hospital will be considered when a) your child is medically stable and b) a safe plan for their treatment outside of the hospital is in place.

Tips for Caregivers

Initiation of Eating Disorders Pathway

- Recovery from an eating disorder is a long-term process. There is no quick fix. However, recovery is possible, and it is very important to get help as soon as possible.
- Rules and restrictions while your child is in the hospital are not punishments; they are needed for your child's safety.
- Eating disorders are not specific to any race, gender, ethnicity, body type, sexual orientation, or socioeconomic status. They can impact anyone. No one is to blame; it is not something you did wrong.
- Your child did not choose to have an eating disorder. Remember that a child with an eating disorder is not purposely choosing to do or say harmful or hurtful things. Be positive, and try not to take these things personally. The illness, or "eating disorder brain," is affecting the decisions your child makes.
- Be firm and consistent with your child. Avoid power struggles. Do not try to trick, bribe, or force your child to eat.
- Be non-judgmental. Focus on feelings, not weight or food. Obsession with numbers, such as weights and calories, is a dangerous part of eating disorders.
- Many families find it helpful to join support groups for eating disorders.
 These groups can help you learn about others' experiences with their children's eating disorders and give you a safe space to express yourself and share your own.
- Take care of your own physical, emotional, and spiritual needs. Your child is being kept safe while in the hospital. It is okay to take breaks away from their bedside to meet your own personal needs.



Appendix G:

Printable Handouts for Patient & Family (SPANISH)

Please print the next 3 pages and distribute upon admission as follows:

To Patient: "Información para el paciente"

<u>To Parent/Caregiver:</u> "Folleto para el cuidador" **and** "Consejos para los cuidadores"

Información para el paciente

Protocolo terapéutico para los trastornos de la conducta alimentaria

A fin de optimizar su recuperación, siga atentamente estas indicaciones si le ingresan en el hospital por trastornos de la conducta alimentaria:

- Se le colocará una sonda nasogástrica para suplir sus necesidades alimentarias adecuadamente, la cual se introducirá por la nariz hasta el estómago. La sonda permanecerá en su lugar desde el ingreso hasta el alta. Si se le sale durante la estadía, la enfermera se la volverá a colocar.
- Un integrante del personal clínico le acompañará en todo momento, incluso cuando use el baño, se duche, coma y cuando salga de la habitación.
- Para garantizar su seguridad, se le pedirá que permanezca en la cama, en el sofá o en una silla mientras esté en la habitación. El personal le indicará si llegara a ser necesario que realice movimientos más frecuentes.
- Solo podrá ducharse una vez al día, con agua tibia únicamente.
- El termostato de la habitación se mantendrá en la misma temperatura durante la estadía, a fin de brindarle un entorno estable. Avise a la enfermera si sospecha que el termostato de la habitación no funciona correctamente.
- No podrá caminar, merodear los pasillos, realizar movimientos repetitivos ni hacer ningún tipo de ejercicio durante su estadía.
- No podrá mascar chicle (goma de mascar) mientras esté en el hospital.
- Cuando tenga que salir de la habitación, se le proporcionará una silla de ruedas, en la que el personal deberá desplazarle.
- Todas las mañanas, una vez que haya orinado o defecado, se le pedirá que se suba a la báscula de espaldas para tomarle el peso. Ni usted verá lo que pesa ni el personal le revelará esta medición, a fin de evitar desencadenantes del trastorno. Deberá vestir una bata y ropa interior únicamente.
- Por favor, no tire de la cadena del inodoro cuando orine o defeque, ya que la enfermera deberá medir la cantidad de orina y heces cada vez que vaya al baño.
- Podrá ir al baño 1 hora después de que termine sus comidas.
- Cuando empiece el régimen de alimentación, deberá consumir las comidas y los refrigerios sentado(a) en una silla (no en la cama ni en el sofá) en un plazo de 30 minutos. Deberá colocar todas las servilletas en la bandeja. Si el personal sospecha que oculta alimentos, le pedirá que se coloque una bata antes de consumir las comidas y las meriendas.
- Debe comer y beber todos los alimentos en la bandeja. Si deja un poquito, se le administrará un complemento por vía oral para suplir el valor nutricional de la porción de comida o de la merienda que no haya consumido. Si se niega a tomarse el complemento por vía oral, la complementación nutricional se le administrará por la sonda nasogástrica.
- Junto con el nutricionista, usted y su familia podrán elaborar un régimen de alimentación que satisfaga sus necesidades nutricionales, teniendo en cuenta las alergias que le hayan diagnosticado y las restricciones alimentarias de índole religiosa.
- Ya que nuestra prioridad es salvaguardar su seguridad, tomaremos en serio cualquier comentario suyo que suponga o implique un perjuicio para su salud o bienestar.



Objetivo del ingreso

Los médicos, psicólogos, trabajadores sociales y nutricionistas que conforman el servicio de trastornos de la conducta alimentaria en el Hospital Infantil All Children's de Johns Hopkins evaluarán y atenderán a su hijo(a).

Nuestro hospital es un centro médico, no un centro psiquiátrico ni un centro especializado en el tratamiento de los trastornos alimentarios. El objetivo de este ingreso hospitalario es, por tanto, estabilizar al paciente para que, tras el alta, pueda iniciar el tratamiento oportuno del trastorno de manera segura.

Durante la estadía se le medirán las constantes vitales y el peso y se le realizarán los análisis clínicos que correspondan. Antes del alta, asesoraremos al paciente y a su familia para identificar el tratamiento del trastorno que le sea más idóneo y eficaz.

JOHNS HOPKINS All Children's Hospital

Folleto para el cuidador

Protocolo terapéutico para los trastornos de la conducta alimentaria

Medidas que se aplicarán durante la estadía en el hospital:

- El nutricionista asignado le orientará para que juntos aborden las necesidades nutricionales de su hijo(a), teniendo en cuenta las alergias médicas y las restricciones alimentarias de índole religiosa. El personal le explicará el tratamiento y le informará sobre el peso corporal de su hijo(a). Por favor, no hable del peso ni de las calorías delante de él o ella, ya que pueden estresarle y desencadenar las conductas del trastorno, lo que sería perjudicial para su seguridad y recuperación.
- Al paciente se le asignará un profesional quien le supervisará en todo momento durante su estadía, incluso cuando use el baño, se duche, coma y cuando salga de la habitación en la silla de ruedas.
- Además de restringir la ingesta de alimentos, es posible que el paciente intente quemar calorías o evitar consumirlas usando otros medios; p. ej. manteniendo la habitación fría o duchándose con agua fría para producirse escalofríos; haciendo ejercicio en el baño, la ducha o la cama, sin que nadie le vea; moviéndose de manera nerviosa; caminando de un lado al otro; bebiendo mucha agua, y tomando laxantes. Durante su estadía en el hospital no permitiremos que realice estas conductas de evasión.
- El uso de aparatos electrónicos, como celulares, computadoras portátiles, consolas de videojuegos con acceso a internet, etc., **no** está recomendado, ya que pueden habilitar al paciente para que cuente calorías y averigüe métodos para quemarlas sin que lo descubran. Las redes sociales son perjudiciales para la salud de los pacientes que padecen trastornos alimentarios. Si necesitan distraerse, podrán ver la televisión de la habitación mientras comen. Si el personal estima que los aparatos electrónicos son perjudiciales para la recuperación de su hijo(a), se prohibirá su uso.
- Los pacientes con trastornos de la conducta alimentaria suelen tener ideas suicidas o deseos de hacerse daño a sí mismos. Estas inquietudes deben abordarse de manera abierta y honesta.
- Salvaguardar la seguridad y la estabilidad de su hijo(a) es nuestra prioridad, así que tomaremos medidas si se sospecha que quiere hacerse daño o desea escaparse.

Medidas adicionales

- El primer o segundo día hábil tras el ingreso, el personal responsable agendará una reunión con los padres del paciente, a fin de explicarles el diagnóstico y el tratamiento adecuado para su hijo(a). Los temas que se tratan en esta reunión pueden generar ansiedad y desencadenar las conductas del trastorno en el menor, por lo que no debe estar presente. De ser necesario, se agendará una segunda reunión.
- Comuníquese con la compañía de seguros médicos después de la primera reunión con el personal, para que les informe sobre el diagnóstico y las necesidades médicas de su hijo(a) y analicen las repercusiones de esta situación en la cobertura. De ser posible, solicite al seguro la asistencia de un coordinador de casos para que le oriente.
- Los servicios que precise el paciente tras el alta hospitalaria dependerán de sus necesidades concretas, pero podrían abarcar desde tratamientos ambulatorios intensivos hasta el ingreso en un centro especializado en trastornos de la conducta alimentaria. El personal estará a su disposición para orientarle sobre los servicios más adecuados y seguros en el caso de su hijo(a).
- El personal autorizará el alta del hospital cuando el paciente esté estable, desde el punto de vista clínico, y cuando se hayan identificado y coordinado las pautas del tratamiento ambulatorio.

Consejos para los cuidadores

Protocolo terapéutico para los trastornos de la conducta alimentaria

- Recuperarse de un trastorno alimentario puede llevar mucho tiempo, ya que no hay una solución rápida para este tipo de enfermedad. Dicho esto, la recuperación se puede lograr, sobre todo si el trastorno se trata cuanto antes.
- Tenga en cuenta que las normas y las restricciones que deben acatar los pacientes en el hospital no son un castigo; por el contrario, se implementan para garantizar su seguridad.
- Los trastornos alimentarios se le pueden presentar a cualquier persona, independientemente de su grupo racial, sexo biológico, etnia, tipo de cuerpo, orientación sexual o nivel socioeconómico, y no son un reflejo de errores ni son culpa de nadie.
- Los trastornos alimentarios no se elijen, simplemente suceden. Si su hijo(a) le ofende o le hiere, recuerde que tiene una enfermedad y que su intención no es hacerle daño. No se ofenda y mantenga una actitud positiva. Esta enfermedad afecta el cerebro y es esta quien, por el momento, controla las decisiones de su hijo(a).
- Sea firme y constante con su hijo(a). No se involucre en peleas o discusiones para ver quién tiene la razón. No intente engañarle, sobornarle ni obligarle para que coma.
- Sea imparcial. Enfóquese en los sentimientos de su hijo(a), no en el peso, en la comida o en las calorías, ya que la obsesión por estos aspectos podría empeorar el trastorno.
- Muchos padres y cuidadores se apuntan a grupos de apoyo sobre trastornos de la conducta alimentaria, ya que así comparten sus propias experiencias y conocen las de otras familias.
- No olvide cuidar de sus propias necesidades físicas, afectivas y espirituales. Su hijo(a) estará a salvo mientras esté en el hospital, así que aproveche para salir y despejarse o para descansar y renovar energías.



Outpatient Eating Disorder Clinic

To best support you in your continued treatment progress after leaving the hospital, we refer all our patients with an eating disorder diagnosis to the JHACH Outpatient Eating Disorder Clinic. This clinic is <u>NOT</u> a substitute for an intensive treatment program you may be starting when you leave the hospital or for weekly therapy. Dr. Reese and her team can continue to provide medical care and mental health assessments for ongoing management and can be considered your long-term eating disorder care team as you continue with your treatment plan and journey to recovery.

This clinic is a unique eating disorder program within the Adolescent and Young Adult Specialty Clinic at Johns Hopkins All Children's Hospital. Your first visit with us will include a 2-2.5-hour appointment, and you will be evaluated by an adolescent medicine doctor, psychologist, and dietitian. We will check vital signs, weight, and other body composition measures. We will consider other testing such as blood work, EKGs, and bone density scans as needed. Based on your individual needs and the treatments you are currently receiving, we can provide recommendations for potential services to consider. We do currently have a wait time for appointments, but patients can be added to our wait list to be called for a sooner appointment when one becomes available.



Dr. Reese is the director of the Adolescent and Young Adult Specialty Clinic within the Department of Medicine. During your visit, Dr. Reese will focus on medical diagnosis and medical complications secondary to weight loss, weight changes, and disordered eating behaviors, as well as recommend medical testing and labs as needed.



Dr. Sobalvarro is a pediatric psychologist in the Center for Behavioral Health. Dr. Sobalvarro will focus on assessing emotional health and symptoms of disordered eating. She will provide recommendations for evidence-based interventions to manage disordered eating behaviors and cognitions.



Jessica Spackman is a clinical dietitian within the Department of Medicine. During your visit, she will assist you with meal planning to help you meet your nutritional needs as well as help you develop a positive relationship with food.



A resident, fellow, or doctor in training will likely meet with you at each visit. The trainee will collect medical history, review medical complications associated with eating disorders, and help coordinate care under the direction of Dr. Reese and Dr. Sobalvarro. You will also meet with our patient service representatives (PSRs) for scheduling as well as our clinical nursing staff members.

Adolescent and Young Adult Specialty Clinic

Outpatient Care Center (OCC) 601 5th St. S. Ste C700 St. Petersburg, FL 33701

P: 727-767-TEEN (8336)

F: 727-767-8711