

Nutritional Rehabilitation Pathway: Overview Guide

As a healthcare team, we aim to provide high quality and safe medical care with a family-centered approach. We do this by using a team of specialists who work together to create the best plan of care for your child. We put safety first while supporting the physical and emotional health needs of all our patients. We hope to partner with you towards achieving our shared goals of safety, healing, and effective transition from inpatient care.

Many, but not all, patients admitted to the Adolescent Medicine Service are here for medical support for severe malnutrition. Every patient has received a medical recommendation for inpatient monitoring and support during the “refeeding” phase of recovery. Our Malnutrition Program, also known as the Nutritional Rehabilitation Pathway (NRP), is evidence based and quality controlled medical clinical pathway. Our program has been proven to prevent severe complications of refeeding, while rapidly restoring the adolescent patient’s metabolism.

Malnutrition can be caused by many different problems ranging from medical to behavioral health diagnoses, including:

- Eating disorders such as Anorexia Nervosa, Bulimia Nervosa, and Avoidant Restrictive Food Intake Disorder (ARFID)
- Disordered eating such as unhealthy dieting and exercise behaviors that do not reach the point of an eating disorder diagnosis
- Underlying medical conditions that cause problems with eating and digestion
- Emotional disorders that cause changes to appetite and can lead to weight loss (for example, depressive and anxiety disorders)

In most situations, there are medical and behavioral factors to consider. For example, many older children and teenagers who may initially lose weight because of a medical problem are at higher risk of developing behavioral signs of an eating disorder. Given how common eating disorders occur in teenagers, it is also not unusual for a medical problem to develop while a teenager is undernourished. This can make it more difficult to diagnose and treat the medical disorder. Many of our practices on the NRP are designed to offset symptoms of eating disorders, while promoting healthy eating practices.

The Malnutrition Program is a partnership between Adolescent Medicine, Behavioral Health, Nutrition, Social Work, Nursing, Psychiatric Technicians, Creative Arts Therapy, and Child Life. Our goal is to ensure that every patient has support to complete the required inpatient nutritional goals. During the inpatient stay, we will offer education to all families about how to support their child at home. You will have the opportunity to practice how to manage eating in the hospital as you prepare for discharge.



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We conduct ongoing quality improvement efforts to improve our services while innovating quality care for your child. Members of our team may discuss opportunities for you and your child to participate in scientific research as we seek to expand the evidence-base around malnutrition in teenagers and eating disorders.

Meet Our Team:

We have a comprehensive team dedicated to successfully caring for your child. Here at CHOP, your child will have a team made up of clinicians from different specialties, including:

- Physicians
- Registered Nurses
- Senior Nurse Aides
- Behavioral Health Clinicians
- Behavioral Health Specialists
(licensed clinical social work or psychology)
- Social Workers
- Registered Dietitians
- Child Life Therapists
- Creative Arts Therapists
- Case Management
- Advanced Practitioners (nurse practitioner or physician's assistant)

The most important member of your child's team is **you** as the parent or primary caregiver. We take very seriously the trust you place in us as we support your child through the initial stages of medical stabilization, and we look forward to transferring that control back to you as we move towards discharge day.

You will be meeting several members of our interdisciplinary care team during this hospital stay. Below are some of the members of our team who will be involved in your child's care:

Adolescent Medicine Trained Physicians

The doctor who is primarily responsible for the inpatient care your child receives is commonly called the attending physician. The Attending is responsible for decisions about your child's medical care at CHOP and pays close attention to how their body responds to refeeding. There is always one attending physician at a time. All of the Adolescent Medicine doctors work closely together to ensure there is consistency and safety as the attending physician will almost certainly change during your stay. Adolescent Medicine is a medical specialty focusing on diseases impacting adolescent development. This specialty requires years of additional training after completing residency in Pediatrics, Internal Medicine, or both. You will also regularly interact with medical students, as well as residents and fellows who are physicians completing the training.

Nurses

Registered nurses (RNs) will provide bedside care for your child and serve as the central point of communication with the interdisciplinary team throughout the day. The nursing team will monitor your child and be available for support during your hospitalization. Your nurse will collaborate with your healthcare team on the plan of care, provide all nutrition, medications, education and training, and assist with activities of daily living during your child's day.



Dietitians

A registered dietitian (RD) with training in the treatment of malnutrition will oversee your child's meal plan and nutrition goals during their hospitalization. The meal plan is a pre-set 7-day rotating menu that contains a variety of different foods. Your team dietitian will also assess prior growth history and determine how much nutrition your child needs to achieve the medical goals. This includes an initial goal weight based on what is needed for their body to restore organ function and physical growth. Your team dietitian will provide education on how to choose food in the hospital and plan meals for when you go home

Senior Nurse Aides

Under the direction of an RN, the Senior Nurse Aide (SNA) may assist in the care of your child. They are responsible for vital signs, meal delivery and observations, and assisting in activities of daily living.

Behavioral Health Clinicians

Behavioral Health Clinicians may be utilized to support your child during their admission if they present with intellectual/developmental disabilities or significant mental and/or behavioral health challenges. They will work to develop and maintain therapeutic rapport and engagement, assist in developing and sustaining coping skills, provide emotional support, maintaining a safe environment, provide patient advocacy, trained in de-escalation, and partner with the care team to work towards achieving your child's individualized goals.

Behavioral Health Specialists

Your child will receive a consultation from the Behavioral Health Integrated Program (BHIP), which consists of psychologists, psychiatrists, and licensed clinical social workers. You will regularly interact with behavioral health specialists in training at various levels and supervised by a licensed clinician (including clinical interns, externs, postdoctoral fellows, residents, and psychiatry fellows). Your child is in the hospital for medical problems related to malnutrition. This malnutrition may be related to an eating disorder or other mental health diagnosis such as depression or anxiety. It is important to remember that your child is here for medical reasons, so the focus of our behavioral health specialists is on getting your child medically safe enough for discharge. A few important points about the services offered by our behavioral health specialists:

- Your primary behavioral health team member will be a psychologist or licensed clinical social worker (LCSW).

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- The Behavioral Health Specialist will:
 - Complete an evaluation to determine if an eating disorder and/or other mental health disorder diagnosis (such as anxiety and depression) may explain or play a role in your child's malnutrition. This evaluation may include questionnaires that will provide more information to help us, and you, understand your child.
 - Provide you and your child with education about the impact of malnutrition on mental health and provide education about any mental health diagnosis that may explain your child's symptoms.
 - Answer questions about what kind of behavioral health treatment may be best when you leave the hospital.
 - Provide information about how to manage the next steps after discharge.
 - Check in on your family and child as needed to promote positive coping while you are in the hospital. The specialists work with other members of your team to help your child receive the treatment they need in the hospital.
- When recommended, psychiatry providers may be involved in your child's treatment. Psychiatrists provide medication to support improvements in mental health functioning.

Social Workers

Social Workers are available to assist with: insurance, school transitions, medical leave paperwork for parents who need support in taking time off from work while their child is in the hospital and coping with the stress of having a child in the hospital.

- The social work team members will help you communicate with your child's school.
- If your child needs a higher level of care, the social work team will help with the process by giving the treatment center information they need.
- The social work team can also provide referral information for behavioral health treatment when your child goes home.

Child Life Services

Child Activity Coordinators help to normalize the hospital environment by engaging patients in developmentally appropriate activities such as: art projects, crafts, games, and music. Certified Child Life Specialists can also work with your child to provide preparation and support for procedures, education about positive coping strategies, and therapeutic activities to support patients and reduce fear, anxiety, and pain while in the hospital. Child Life staff can tell you about unit and hospital programming such as: Free Time in the teen room, creative art therapy groups, special events in the hospital.



Creative Arts Therapists

Creative Arts Therapy (Art Therapy, Music Therapy, and Dance/Movement Therapy) groups are provided by master's level, board-certified, and registered mental health professionals to promote positive coping and resiliency during the hospital experience. Individual sessions may be provided on a case-by-case basis to provide additional layers of psychosocial support. Creative Arts Therapists assess clinical needs and put into action a plan to support emotional, social, and physical health for patients of all ages. They use both non-verbal and verbal processes. No previous experience in creative arts is necessary and we encourage all of our patients to participate in this programming.

Hospital School Program

Highly qualified Pennsylvania-certified teachers strive to help children, who are in a K-12 school, develop and maintain academic skills by participating in the familiar and normal activities of school. This helps children cope by reducing the stress of hospitalization.

Parents and Caregivers

You are some of the most important members of our team as well because you know your child better than anyone else. You are the expert when it comes to your child. We encourage caregivers to be involved in your child's care while they are in the hospital. This will allow you to learn skills and practice them here to help your child when they leave the hospital.

What to expect during your child's admission?

Hospital Environment:

- On arrival, your nurse will show you around the unit and to your child's room. Some of our rooms are double rooms, so your child may be sharing a room with another patient. Your room assignment may change based on your needs throughout your stay with us.
- The Hospital strives to provide a safe environment for all patients who are assessed to be a threat to themselves or others. To provide a safe environment, the staff will conduct a search of patient rooms and patient's personal belongings on admission and throughout the stay. This is to make sure that there are no items that could be used by your child as a way to hurt themselves. Patient consent to be searched is not required, but it is desired prior to starting this search.
- While we want your child to be comfortable during their stay with us, we do ask you to limit the number of belongings that you bring for them.

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- Your/your child's medical team are available to provide medical updates on a daily basis. Most inpatient notes will likely not be shared to MyCHOP in real time. This is due to a high risk of physical harm when patients undergoing nutritional rehabilitation are able to view daily updates in real time. The decision to share a note will be at the discretion of your child's health care team in the interest of you/your child's safety. If you have questions or concerns about our information sharing practices, please discuss with your attending physician.

Medical Evaluation and Monitoring

- The medical team will do a thorough medical evaluation (history, physical exam, blood tests) to make sure there are no other health problems causing your child's malnutrition or weight loss.
- They will watch for other problems that sometimes occur with weight loss such as a slow heart rate, dizziness, abdominal pain, low temperature, and abnormal blood test results (electrolytes, liver function, kidney function).
- Your child will wear a heart monitor during their hospital stay until their doctor recommends removing this monitoring. All patients will have an EKG on admission. Every morning we will check your child's heart rate and blood pressure while lying down and standing up.
- Your child's heart rate, blood pressure, and temperature must all be in a safe range before discharge.
- During the beginning of your child's treatment, they are at risk of a dangerous condition known as refeeding syndrome. This happens when there is a sudden shift in fluids and electrolytes and can lead to dangerous heart problems. To monitor for refeeding syndrome, we will do blood tests often. If the electrolytes are abnormal, your child may need to take electrolyte supplements as recommended by their medical team.

Daily Schedule

A schedule of structured mealtimes, unit activities and groups will be provided based on each individual patient's plan of care.

The daily schedule is designed to allow your child the opportunity to engage in therapeutic and recreational activities that provide positive reinforcement and support. The daily schedule also ensures that quiet, restful activities are provided in the period of time after meals. The daily schedule encompasses meal plans, after meal periods, child life/creative art therapy/school activities, and gradually advances physical activity to limit unnecessary energy expenditure. The meal and after meal periods of the daily schedule are described in detail below.

Meal Plan:

- Food is one of the most important medicines that your child needs to get well. All patients are prescribed a set amount of nutrition. The amount of nutrition needed is determined by your child's Registered Dietitian (RD) and ordered by a physician. The amount of nutrition increases each day according to the Nutritional Rehabilitation Pathway (NRP) until your child is medically stabilized and showing consistent weight gain.
- The hospital menu is pre-selected and will be delivered by the dietary team prior to each meal. Modifications to the menu are only made for the following reasons: food allergies and religious/cultural dietary constraints. If your child is not able to complete the food offered, they will be provided with the caloric equivalent in a nutrition supplement, like Boost, to drink.
- If the food or supplement are not completed, a naso-gastric (NG) tube will be placed in your child's nose and down their throat to get liquid nutrition to the stomach, so they can receive the remaining nutrition. Medically, we need to ensure that your child's nutritional needs are met.
- Use of electronic devices are not permitted during meal and snack periods. This includes cell phones, tablets, computers, tv and other personal electronic devices such as AirPods, smart watches, headphones, or other personal electronic items determined by the care team.
- In the 60 minutes after meals, and 30 minutes after snacks, your child can only engage in restful activity. This promotes digestion and ideally distraction. Restful activity includes any quiet activity that your child can perform while seated in their chair or resting in bed. They are not allowed to engage in any physical activities and cannot go to the bathroom during this time.
- Near the end of your child's stay, the dietitian will teach you how to plan and choose food with high caloric densities and plan meals to reach calorie goals. Once this has occurred, you will be able to order meals for your child.

The timing of eating and after meal periods can be found in the chart below.

	Notification	Time to complete	Boost time to complete	After meal period (restful activity only)
Meal	15 min	30 min	15 min	60 min
Snack	5 min	15 min	15 min	30 min

Meal and snack times are as follows:

Meal Plan	Meal Plan A	Meal Plan B
Breakfast	7:30 am	8:30 am
AM Snack	9:30 am	10:30 am
Lunch	12:00 pm	1:00 pm
PM Snack	2:00 pm	3:00 pm
Dinner	5:30 pm	6:30 pm

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Meal and After Meal Period Guidelines

Because our program is focused on improving medical problems related to malnutrition, we require a high level of observation, structure, and support. This is especially true during all eating periods given the importance of making sure that your child is eating their full nutritional recommendation. Even if your child does not have an eating disorder diagnosis, our program requires observation during all meals and snacks.

- **Meals Out Of Rooms (MOORS)**

- Structured meals will be conducted in a group setting in a separate room on the unit, unless otherwise deemed by the medical team. Your child will remain in the dining room for the duration of their meal, boost, and rest time. After the rest time is completed, your child will be escorted back to their room by a staff member. If medically necessary, your child may need to use a wheelchair to get to and from the meal room. The group will consist of other patients who are also on the Nutritional Rehabilitation Pathway (NRP) and will be supervised by Behavioral Health Clinician
- Baggy clothing, hooded sweatshirts, and boots are not permitted in the MOORS room. T-shirts, fitted long sleeves or short sleeves are the preferred clothing. Your child will be asked to return to their room and instructed to change into a gown if no other options are available due to concerns for hiding food.
- Your child can talk to other patients while eating. The conversation needs to remain positive and not focus on weight, food, calories, stressors, or treatment to decrease the potential of triggering others.
- Use of personal electronic devices are not permitted during meal and snack periods. This includes cell phones, tablets, computers, AirPods, smart watches, headphones, or other personal electronic items determined by the care team. This allows your child time to focus on eating and respects the privacy of all patients and staff in the dining room.
- Your child may bring a book or schoolwork to the dining room to use if they complete their meal before the end of the meal period. The team will also provide restful activities for your child if needed. After completing the meal, your child will either return to their bed, or be escorted to scheduled restful (seated) activities in the teen room or classroom.

- **Parents observing meals**

- If your child does not participate in Meals Out Of Rooms program and you would like to be the one supervising the meals, your team may approve this request based on their assessment of your child's needs. If you commit to observing meals, we ask that you supervise all meals and snacks and the appropriate after meal periods. If you are not able to be present for certain meals, your child will have meals in the MOORS room, unless otherwise determined by your team.

Physical Activity

- A goal of the daily schedule is to limit opportunities for your child to engage in physical exercise. This is important in order to restore your child's energy balance. This means that the energy input in the form of food equals the energy use needs for your child. We know that significant energy is needed to heal physically from malnutrition, and to restore ongoing growth and development. In a malnourished state, most youth will not retain the same physical stamina and agility as they may have been accustomed. Therefore, limiting physical activity at this point in their recovery benefits your child by reducing risk of injury. Additional calories would need to be added to their meal plan to offset any excess energy expenditure.
- On the NRP, physical activity is gradually advanced based on meeting medical goals.
- The schedule is built so that quiet restful activities are planned in the after meal period. If there is a barrier to participation in scheduled activities, an alternative plan will be needed for your child to ensure they are engaged in quiet restful activity in the after meal period.
- Common symptoms with eating disorders include compulsion to exercise or purge calories in some way. When this becomes evident, it may require 1:1 supervision, continuous cardiac monitoring, or other schedule changes.

Education

During your hospital stay, the healthcare team will provide education and training on how to support your child in 1:1 sessions and caregiver group education sessions.

Patient and Family Education

In addition to the NRP orientation packet, you will receive the following education during your hospital stay:

- Behavioral Health Education
- Nutrition Education
- Discharge Planning Education

Caregiver Group Education Series

- Caring for a child who is malnourished is very difficult, so our goal is to teach you strategies to help your child to get well. We strongly recommend that all caregivers for children on the Nutritional Rehabilitation Pathway (NRP) attend our **Caregiver Education Group Series** to learn more about how to support their children in the next stages of care.
- All adults that are going to be involved in the child's recovery (grandparents, aunts/uncles) are invited to attend.
- All details can be found Nutritional Rehabilitation Pathway (NRP) Group Education Series handout located in the NRP Packet. You can reach out to your Behavioral health and / or social worker for any questions.



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