

Restoring Nutrition: What to expect during your child's hospital stay

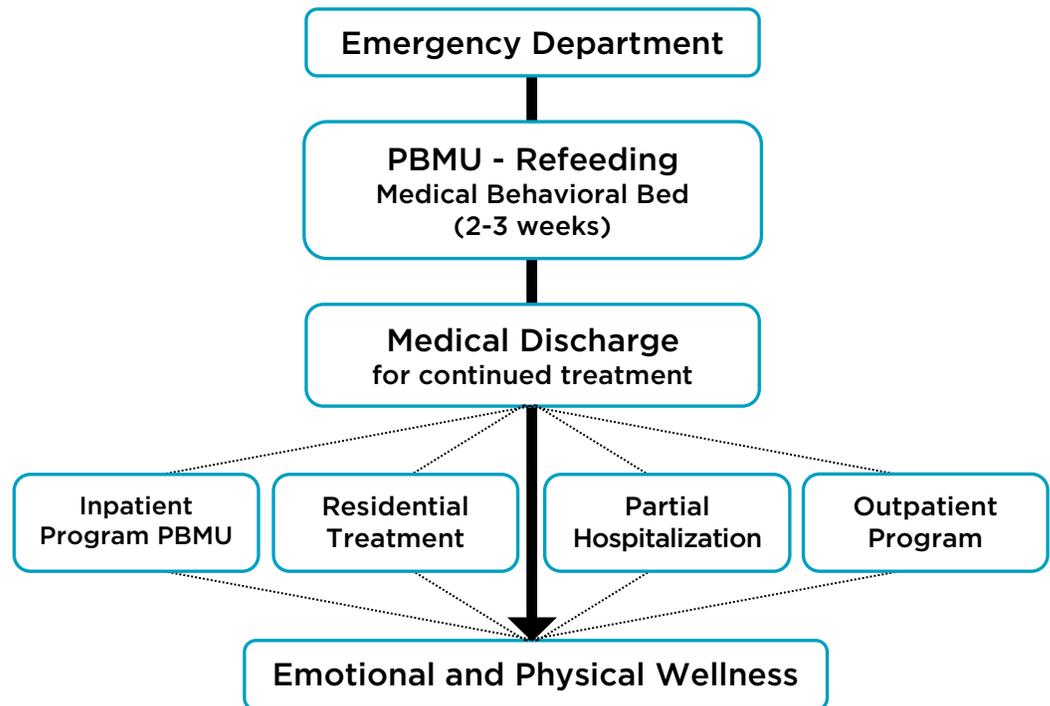
“Coming to the PBMU saved my child's life, no question. And the knowledge we gained during her stay will help us both navigate the world for the rest of our lives.”

Why does my child need to stay in the hospital?

Your child has severe malnutrition after a period of food restriction or starvation. They need to stay in the hospital to carefully restore normal eating patterns and stabilize their health. We call this process refeeding. To refeed your child safely, they need to be closely monitored in a hospital, most often for 2 to 3 weeks.

What will happen during my child's hospital stay?

To provide the best care for your child they will be medically stabilized in a Medical Behavioral Bed (MBB), which is in a special section of our Psychiatry and Behavioral Medicine Unit (PBMU). Here, we provide medical and behavioral monitoring of your child with staff trained to help your child meet their nutritional needs.



Rarely, children may need to be on the Medical Unit to treat or monitor critical medical problems such as very low heart rate or body weight, or severe electrolyte abnormality, before moving to the PBMU for the rest of their stay.

Who will care for my child?

You

You are an important member of your child's healthcare team. You know your child best. We will work with you to make decisions and treatment plans for your child. You will be trained in providing meal support and given opportunities to practice this with your child during their hospital stay. If you have any concerns about your child's care or the treatment plan, please talk to us right away. We want to hear your concerns, and it is very important that we align as a team to help your child. So, we ask that you talk to us about any concerns in private away from your child.

General medical team

They are your primary medical team and will oversee your child's care and manage their daily treatment while in the hospital. There is someone from the General Medical team in the hospital 24 hours a day, every day of the week.

Adolescent Medicine

Medical doctors who specialize in the care of adolescents and young adults and have expertise in refeeding patients with starvation. They will monitor how your child's body responds to the nutrition and provide medical treatment advice to the General Medical team.

Nutrition

A registered dietitian will meet with you and your child to do a nutrition assessment. They will set food and fluid goals, and provide education. They will also help you develop a nutrition plan for home.

Psychiatry/Psychology

Mental health professionals provide diagnostic assessment, psychoeducation, emotional support, and guidance on anxiety management. This team also provides mental health care coordination for after the hospital stay, including mental health treatment referrals.

Registered nurse

A licensed nurse who supervises and provides most of your child's daily care and education. They are the main contact with other members of your child's healthcare team.

PBMU coaches

Pediatric Mental Health Specialists (Coaches) lead meal support and provide supervision and support for your child throughout the day.

Medical Care

Why does my child need medical care?

Your child's body is starving. They are not eating enough food to keep up with what their body needs to function and grow. Their body is starting to break down tissue from the heart, brain, liver, intestines, kidneys and muscle to get the energy and nutrients it needs to function. Your child's body is slowly starting to shut down. They need medical care and feeding right away to prevent life-threatening health problems.

What are the signs and symptoms of starvation?

- To conserve energy, the starving body slows down and we see low heart rate, blood pressure and body temperature
- Weight loss
- Feeling very tired
- Thinking or speaking more slowly
- Being more irritable or showing personality changes

How do you treat starvation?

We treat starvation with gradual refeeding over 2 to 3 weeks. This means we give your child small amounts of food that their body can tolerate, and increase it gradually until we find the amount they need to be healthy. If a starving child eats too much food all at once they may get very sick, and even die, from a process known as refeeding syndrome (RFS).

Our goal of feeding your child in the hospital is to:

- Nourish them safely
- Monitor and manage how their body responds to the nutrition
- Provide support to help them learn how to nourish their bodies

What is refeeding syndrome?

RFS is a potentially life-threatening complication that can happen in the first 2 to 3 weeks when a person in a starvation state begins to receive nourishment. Complications can arise when the body cannot tolerate the amount of nutrition and fluid provided, which is why we follow a carefully designed refeeding diet. This also explains why your child must eat exactly what is sent and why we check weights, labs, and fluid-ins and -outs very carefully during this period.

Nutrition Intervention

What will my child be given to eat and drink?

Our goal is to help your child consume a variety of foods that provide enough energy (calories) and nutrients to get them medically stable.

Important things to know about meals and snacks:

- We will give your child well balanced meals and snacks based on an individualized plan from their dietitian.
- Your child will be served breakfast, lunch, dinner and 3 daily snacks, as they need to eat every 2 to 3 hours to restore their health.
- We will expect your child to finish meals within 30 minutes and snacks within 15 minutes.
- Your child is not allowed to choose their own food and no diet foods or caffeine is allowed.
- You may not provide additional food or drink.

Please talk to the dietitian if you would like more information.

"I highly recommend going to the PBMU, even though it seems scary, it's actually warm and welcoming, full of love and education."

Parent of a former patient

What if my child does not finish a meal or snack?

Food is your child's medicine and they need to finish 100% of all foods and drinks, including condiments. If your child does not finish a meal or snack, we will give them a nutrition supplement to replace the uneaten portion. They will be given 10 minutes to drink the supplement.

What if my child does not drink the nutrition supplement?

We understand that finishing meals will likely be the most difficult part of the hospital stay for your child, and also the most important. If your child is unable to finish the nutrition supplement, the nurse will place a nasogastric (NG) tube to help them. This is a tube that is inserted into the nose and allows liquid nutrition to reach your child's stomach. We do this the first time your child is unable to finish the nutrition supplement, as they need this vital nutrition. After the NG is placed your child will be encouraged to complete every meal and snack by mouth.

What if my child is on a vegetarian diet?

We are unable to meet this dietary request unless it is a lifelong practice. During nutritional restoration, your child's energy (caloric) and nutrient needs are very high and their bodies will not be able to tolerate the volume of food needed with a vegetarian diet. Please tell the dietitian about any family religious or cultural food practices.

What is Meal Support?

Meal Support is a facilitated mealtime session between your child and an adult who models healthy and appropriate eating behaviors. On the PBMU, coaches provide group meal support and parents are encouraged to attend. We recommend parents and caregivers attend the Meal Support Training as soon as possible to practice meal support with their child. See the "Meal Support Training" handout for more information (www.seattlechildrens.org/pdf/PE1371.pdf).

What happens with meals when we go home?

During your child's stay, the dietitian will meet with you to review recommendations specific to your child's needs, including:

- How often your child should eat meals and snacks
- Choosing a variety of foods
- Understanding what amounts of food are enough
- Adjusting to going back home

Psychiatry and Behavioral Medicine Care

What is the PBMU?

The PBMU is an acute care unit in the hospital to stabilize mental health crises in children and adolescents ages 3 to 18 years.

Is this solely an eating disorder unit or program?

No, we also have patients staying on the unit for depression, anxiety, and behavioral challenges, including psychosis and Autism.

Why is the PBMU the best place for my child?

Difficulty with eating and eating disorders are behavioral and mental health disorders. Your child needs the expertise of both medical and mental health providers to treat the medical problems that result from their unhealthy eating behaviors. We have specially designated beds on the PBMU called "Medical Behavioral Beds" (MBBs). They are medical beds and our nurses are present 24 hours a day. We are able to provide the supervision and support your child needs to monitor medical problems and manage anxiety during the refeeding process.

How long will my child be on the PBMU?

Most patients admitted to the unit for refeeding need 1 to 3 weeks to be healthy enough to safely go home and start the next phase of their treatment.

What kind of help will my child get for their eating disorder?

Our approach for helping your child includes:

- Meal support with trained coaches
- Medical care including close monitoring for medical problems during refeeding
- An activity plan based on your child's recovery level; most children use a wheel chair to conserve energy when restoring nutrition
- Parent education and training
- Plan for transition to home

How will my child be supervised while on the PBMU?

Patients are supervised at all times and most patients are in groups during the day. If a patient is in their room, we check on them every 15 minutes.

Your child will have special supervision, including:

- Being in the line of sight by a Meal Support trained staff or parent for one hour after meals and snacks
- Bathroom restriction for 1 hour after meals and snacks. If the patient is unable to wait, a coach will listen with the door slightly ajar to keep your child safe
- Bathroom monitoring with the door slightly ajar before they are weighed to ensure an accurate weight measurement

What if a patient is acting unsafe on the PBMU?

If a patient is being unsafe we intervene immediately. We give them space so they can make a healthy choice while making sure all other patients are safe. We may, in some cases, move the patient to a space where they can calm. This may briefly delay scheduled activities, but not medical care.

To Learn More

- Psychiatry and Behavioral Medicine Unit 206-987-2195
- Ask your child's healthcare provider
- www.seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your child's nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

What can my child have during their stay in the PBMU?

- Your child can bring their own clothes, bathroom products, and items to entertain themselves.
- Cell phones, iPads and laptops are not allowed on the unit. They may bring a music player without Internet access.
- Your child should wear loose, comfortable clothing (jeans or tight-fitting clothing are not allowed).
- For more information about what items are allowed see "Patient and Visitor Information for the PBMU" (www.seattlechildrens.org/pdf/PE2018.pdf).

How can we be involved?

Family involvement is important to recovery. We encourage you to:

- Attend the PBMU skill building groups alongside your child.
- Visit your child any time day and night. There is room for one parent or legal guardian to stay with your child overnight.
- Attend the 2-hour Meal Support Training and the 30-minute check-in with the PBMU Parent Support staff.

Who do I talk to if I have concerns while we're on the PBMU?

Please feel free to talk to a PBMU coach or one of the Charge Nurses. If they are unable to help you, then the PBMU Leader on Call (LOC) may be reached by a staff member or yourself by calling the Seattle Children's operator at 206-987-2000.

What happens if my child goes to the medical floor first?

If your child has very low body weight, very low heart rate, abnormal electrolytes or other critical medical problems, we will recommend a brief (0 to 5 days) stay on the general medical floor.

As your child is critically ill, they will be on bedrest and only allowed out of bed to use the bathroom. Meals will be provided; however, there are no Coaches on the medical floor to provide meal support to help your child complete meals and snacks. The medical floor is not equipped to provide the behavioral monitoring and support needed to restore nutrition and reach medical stability.

Once your child is medically stable, they will be transferred to a Medical Behavioral Bed on the PBMU where they will benefit from continued medical monitoring while also learning balanced nutrition and eating skills.