

The Feeding Disorders Program Family Handbook



Behavioral Psychology
at Kennedy Krieger Institute



TABLE OF CONTENTS

Our Program	1
Our Team	2
Evaluation and Assessment	3
Behavior Issues and Feeding Disorders	4
What to Expect During Your Child's Stay	5
Our Menu Options	6
The Feeding Playroom	7
Your Role in Your Child's Care	8
Therapeutic Leave of Absence	10
Discharge and Follow-Up: After You Leave Our Program	11
Information for Day Treatment Patients	12

“This experience has been life-changing for our family. Kennedy Krieger made it possible for our family to live a normal life. We can go out and do all the activities you dream of doing with children. ...We can focus now on our children, rather than on our children’s eating.”

– Rob and Anne, Parents



Our Program

We offer a full continuum of care, including inpatient, day treatment and outpatient treatment services. We emphasize an integrated, interdisciplinary and collaborative approach through patient care, research and administrative services to accomplish our mission. Our methods have become a national standard in the treatment of pediatric feeding disorders.



Our Team

The variety of factors contributing to a pediatric feeding disorder demands a coordinated effort from a team of experts assigned to your child's care. The Feeding Disorders Program uses an interdisciplinary team approach to evaluate and treat your child's feeding difficulty. Throughout your child's treatment in the program, staff members from a variety of disciplines will work together closely, discussing your child's progress and suggesting ways to decrease food refusal and increase appropriate eating. As the primary caregiver, you know your child best; your input is critical. You will also take an active role as you learn how to incorporate treatment approaches into your child's home life.

Our interdisciplinary team includes these specialists:

- Behavioral psychologists
- Child life specialists
- Feeding specialists
- Nurse practitioners
- Nutritionists
- Occupational therapists
- Pediatric gastroenterologists
- Pediatricians
- Playroom specialists
- Social workers
- Speech-language pathologists
- Support staff members

Evaluation and Assessment

Upon admission to the program, you and your child will participate in several evaluations designed to give the treatment team a better understanding of your child's feeding disorder and current family practices around meals. You will be asked to complete questionnaires to provide our specialists with necessary background information about you and your child. We will also ask you to conduct several meals with your child here at the Institute, as you would at home, so we can see how your child responds to various meal events. Following these assessments, the feeding therapist will conduct meals with your child.



These evaluations are designed to help your Kennedy Krieger team develop a treatment plan tailored to your child's unique needs. All program team members are involved in creating your child's treatment plan; therefore, each one will need to conduct evaluations from his or her respective discipline to better understand your child's feeding difficulty. We ask that you be patient with the process and remain readily available during this critical period, as your input provides important information to the team.

“A feeding disorder is not caused by one thing alone, and working on one aspect alone is not necessarily going to solve it. Because the disciplines at Kennedy Krieger really come together, we have the best ability to work with the problem and come up with a solution.”

– Liz Enagonio, MS, RD, CSP, LDN, Kennedy Krieger Nutritionist



Behavior Issues and Feeding Disorders

Research has shown that behavioral approaches to the assessment and treatment of children with feeding disorders help increase appropriate eating and decrease inappropriate behavior at meals. Our behavioral psychologists work with the interdisciplinary team to treat all aspects of your child's feeding difficulty.

When treating your child, our behavioral psychologists use a data-based, behavioral assessment approach and treatment based on behavioral science and applied behavior analysis. Applied behavior analysis is a science that focuses on what children and caregivers do and say in an attempt to understand the function or purpose of the child's behavior. A behavioral assessment includes an evaluation of caregiver-child mealtime interactions to identify situations that result in inappropriate behavior, and to identify common caregiver responses to that behavior. This information will help us plan an individualized treatment approach for your child.

Our behavioral psychologist will also conduct additional behavioral assessments with you and your child. These assessments will include direct observation of your child's mealtime behavior under different situations. The behavioral therapists will record how your child responds to these situations (e.g., number of bites taken), which may include the following:

- The presence of preferred foods versus non-preferred foods.
- The presence of higher textures versus lower textures.
- The use of preferred toys or foods for taking a bite of food of the therapist's choice.

Your child's behavior during these sessions will help the behavioral psychologist plan a treatment approach tailored to your child's needs.



What to Expect During Your Child's Stay

Treatment will begin upon completion of initial behavioral and meal assessments. Initially, your child's refusal, including crying, may increase significantly. However, it is our experience that these behaviors decrease with accurate and consistent implementation of the feeding treatment and should not be a cause for major concern. Our program collects data during every session and reviews the data daily to evaluate your child's progress. Our treatments are based on proven approaches, with the goal of helping your child and family establish healthy eating/feeding routines.

Once food refusal is low and your child begins accepting and swallowing bites, we may begin to work on additional goals, including increasing volume, texture or cup drinking. Depending on the severity of your child's feeding disorder, your child may not be eating like other children upon discharge. Although the long-term goal is always to have your child eating like other children, this process may take some time. Your child may need continued treatment and follow-up in our outpatient clinic.

As caregivers, you are given a full range of possible or feasible treatment options and outcomes, and your opinion of these options will be given full consideration. You may elect a less intrusive treatment, which may result in slower progress. When discussing treatment options and recommendations, the treatment team will explain the rationale for the options, demonstrate the procedures, identify any concerns you may have and address them as needed, and provide alternative recommendations and compromises when requested and feasible. The treatment team and caregivers will also agree upon a specific time period during which to evaluate change.



Our Menu Options

Your child's food will be prepared prior to each meal session. When appropriate, meals consist of a food item from every food group—fruit, starch, protein, vegetable—and a drink. Foods will be presented in whatever texture is most appropriate for your child (e.g., puree, junior, wet ground or regular texture). For allergy-sensitive children, doctors' orders pertaining to allergy-safe diets will always be followed. Cultural/religious dietary guidelines will also be followed. As a caregiver, you will be involved to the maximum extent possible in determining your child's menus. Although we supply all the food your child will need, if there are specific foods or dishes that we are unable to supply, you are welcome to bring them from home.

A typical meal schedule:

Breakfast: 8:30 or 9:30 a.m.

Lunch: 11:30 a.m. or 12:30 p.m.

Dinner: 3:30 or 4:30 p.m.



“The feeding program at Kennedy Krieger is amazing! We gained another family. Joshua came in eating only fries and drinking from a bottle at age 6. Now he drinks from a cup and eats a variety of foods.”

– Laura, Parent



The Feeding Playroom

The playroom is a safe and fun environment that provides patients with an opportunity to play independently, or with other children, throughout the day when they are not in treatment or evaluation sessions. Patients' daily schedules are posted, and feeding therapists will often pick up children from this central location. Feeding playroom specialists are available to help facilitate developmentally appropriate activities. You are encouraged to leave your child in the playroom during supervised hours. When the playroom is not supervised, your child may use the playroom when accompanied by you or another caregiver.

Please note: Siblings and friends are not allowed in the playroom or treatment rooms unless special arrangements have been made.



Your Role in Your Child's Care

One to two weeks after admission, a family steering meeting is held with your child's entire interdisciplinary treatment team. At this meeting, you and the team will discuss the results of the initial meal assessments, determine treatment goals for your child's treatment, and outline what services will be provided and how often. This meeting will be an opportunity for you to voice any specific goals, questions or concerns you have about your child's treatment.

Throughout the treatment process, you and the treatment team will continue to meet informally. You may also speak with your child's clinical specialist to request formal conferences with the team during your child's stay.

A critical component of the program is caregiver training. Once an effective mealtime protocol has been developed, caregivers will be trained to implement it. To ensure that progress made during the program is generalized to other settings, caregivers practice implementing the protocol in a variety of settings, under the supervision of a behavioral feeding therapist.

We've found that consistency is very important. It is preferable to have all care providers using the same feeding protocol so that your child can learn what is expected during meals. It's also important that other caregivers be trained to feed your child in your absence. If there are other people, such as a therapist, teacher, babysitter or relatives, who routinely feed your child and whom you would like to have trained, please discuss this with your child's primary therapist.

“My 7-year-old son came to Kennedy Krieger in order to diversify his food choices. The staff was second to none, knowledgeable and compassionate in helping overcome my son's adverse behavior.”

– Susan, Parent





Therapeutic Leave of Absence

A therapeutic leave of absence (TLOA) for inpatients is a brief period of time during which you and your child may leave the program. The purpose of the TLOA is to see what it will be like to care for your child at home and in the community before your child's discharge. The TLOA will be discussed with you before and after it occurs. Depending on the needs of your child and your family, you may take your child home or into the community, or you may independently care for your child in the hospital.

A TLOA will be recommended when you and the interdisciplinary team agree that your child is ready to have time out of the hospital. Because of the number of therapies your child will receive during the day, the time allotted for a TLOA occurs in short blocks. Our policy is that a patient may be allowed up to eight hours of therapeutic leave across a seven-day week (Sunday morning through Saturday evening). To be sure your child does not miss needed therapies, we ask that a TLOA not exceed four hours. You can divide the eight hours in different ways: for example, two four-hour TLOAs, eight one-hour TLOAs, or four two-hour TLOAs.

Discharge and Follow-Up: After You Leave Our Program

Before officially discharging your child from the Feeding Disorders Program, a follow-up appointment will be scheduled at the outpatient clinic for a date approximately four to six weeks after discharge. Typically, therapists will call you shortly after you arrive home to see how things are going and ask if you need assistance. You are also welcome to call the therapists to discuss your child's progress. If you are unable to attend the follow-up appointment, other communication methods, such as phone contact or videotaping of meals, may be used to support your family and monitor progress.



“After eight weeks, we left Kennedy Krieger’s program with a strong foundation, equipped with the tools to continue to help our son grow.”

– Parent



Information for Day Treatment Patients

Before every breakfast meal, all children must be checked in (that is, they must be weighed and have their temperature taken) at the nurse's station. If your child takes naps, please bring your own sheets and pillows. A Pack 'n Play crib or cot will be set up for your child's nap in a session room. Caregivers may also provide any night lights, monitors and music. Many caregivers stay with their child during naptime, either in the main room or in the observation room. Others bring a baby monitor from home so they can eat, relax or do other activities away from their child.



We provide a lounge for caregivers that is furnished with sofas and a refrigerator, TV, microwave, Keurig coffee machine and computer with internet access. This lounge is for parents and caregivers only. Lockers and locks are available to store your belongings until your child's discharge. Also, feel free to bring any food or drinks you may want to offer your child outside of mealtime. You will be given specific times when you may feed your child outside of meal sessions.

Please note that sessions may be terminated if patients are continually late for meals or miss scheduled appointments. Please be prompt to all sessions. Don't forget to call the Feeding Disorders Program office and your child's feeding therapist at **443-923-2740** if your child is sick, or if you are going to be late for the morning feeding session.

“The program was an absolute life-changer for my son and our whole family. It's hard to even express how much it has done for us, or the gratitude we have for this exceptional program. ... It is the most liberating feeling, now that he can eat the same food our family has, for every meal!”

– Brooke, Parent



Contact Information

For more information or to make a referral to the Feeding Disorders Program, please call **443-923-2740**, or call toll-free at **888-554-2080**. TTY users, please contact us at **443-923-2645**, or dial **711** to make a Maryland Relay call.

Mailing Address

Feeding Disorders Program
Kennedy Krieger Institute
707 North Broadway
Baltimore, MD 21205

FeedingDisorders.KennedyKrieger.org

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Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Kennedy Krieger Institute provides care that preserves cultural, psychosocial, spiritual and personal values, beliefs and preferences. Care is free from discrimination based on age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression, including transgender. We encourage patients and families to become active partners in their care by asking questions, seeking resources and advocating for the services and support they need. 01/2019

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