Welcome to the Sanford Feeding Disorders Program. We know going through this program can be both challenging and difficult. We are here for you and your child. We consider it a privilege to care for you and your child. This Family Guide was created to provide you and your child with the needed information while your child is in our care. Our team is here to support your child and family. If you have any questions please feel free to ask anyone on the healthcare team.

_Sanford Feeding Disorders Staff_
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About Our Program

The Sanford Pediatric Feeding Disorders Program is an intense treatment for children. It is for children from birth to 12 years old. It covers all developmental abilities. Our team has the training and experience in many different pediatric feeding and swallowing problems.

The setting where we work with your child has treatment rooms with technology which allows the caregiver to:

- Watch staff and children during the feeding sessions.
- Be fully involved in the treatment plan throughout all phases of the program.

Partial Hospital Feeding Program

- To be part of this program, your child and family must make a 6-8 week commitment.
- Your child will be in active treatment with the feeding disorder team for about 20 hours each week.
- Your child will work towards treatment goals. These goals will be decided by the treatment team and your family when your child is admitted to the program.
- The goals will be based on your child and family’s individual needs. Some of these goals may include, but are not limited to:
  - Reduce or eliminate supplements
  - Reduce or eliminate tube feedings
  - Reduce or eliminate behavior problems that happen during mealtime.
  - Increase other kinds of foods your child will eat.
  - Increase how much your child will eat and drink.
  - Increase the amount of other food textures your child will eat.
  - Weight gain
  - Caregiver training

Things to know

Hours
- Monday-Friday
- 8:00 AM – 5:00 PM

Playroom
A playroom for your child is available.
- It is a safe and fun environment.
- It allows your child to play by themselves or with other children attending the program throughout the day when they are not in session.
Napping
• Cots are provided for children who need to rest or take a nap.
• You will need to bring sheets/blankets/pillow for your child.

Lockers
Lockers are provided for your child’s use.
• Your child’s belongings may be stored in the locker until discharge.
• There are no locks for the lockers. You will need to bring a lock to use on your child’s locker.

Food
• You can bring in food or drinks for your child you may want them to have in between mealtime.
• You will be told what times you can feed or your child can have this food in-between mealtime.
• You may want to bring a cooler to store drinks and food that needs to stay cool.
• If you want to buy food, you may use our cafeteria. The cafeteria is located in the hospital across the street. There is an underground tunnel for you to use.
  o Hours
    ▪ Breakfast: 6:30 AM – 10:00 AM
    ▪ Lunch: 10:45 AM – 1:30 PM
  o Directions
    ▪ Take the elevator from 3rd floor to the basement.
    ▪ Take a right after exiting the elevator.
    ▪ Cafeteria is on the 1st floor of the hospital. You may use the elevator or stairs at the end of the tunnel. On 1st floor, take a left.
    ▪ Down the hallway, enter the main doors to the hospital.
    ▪ Turn right by the gift shop.
    ▪ Continue walking down the hallway. The cafeteria will be located on your left.
• Coffee Bar – There is a coffee bar located in the dining area of the cafeteria and on the second floor of the clinic.

Use of Social Media
While your child is in treatment, we have guidelines in place for the use of social media. Parents/caregivers cannot post any pictures and videos on their social media sites. This includes, but not limited to Facebook, Twitter and any other sites you are a part of. This includes:
• While you are observing a treatment session.
• Any other children and families who are involved in a treatment program at Sanford.
• Any Sanford staff person.
Other Items
Some suggested items for you to bring for you or your child to have while you are here:
- Chargers for phone or electronic devices
- Head phones
- Electronic devices you or your child use
- Extra clothing for your child
- Toys to use as rewards for your child
  - Favorite toys are **only** to be used when they are in a feeding session. This will help to motivate them to participate in the feeding session and engage in the correct behaviors if they know they can have their favorite toy.
  - Other toys may be played with when they are not in their feeding session.

Be sure to label **all** your personal items. We do not want them to get mixed up with other items from other families.

Parking
You may park on the 1<sup>st</sup> level of the parking ramp. After you enter the door, take the elevator up to the 3<sup>rd</sup> floor.

Directions to the parking ramp
- Take the elevator to the basement level.
- Take a right to the underground hallway.
- Take a right in the tunnel.
- Walk to the elevator for the parking ramp.
- Take elevator to the 1<sup>st</sup> floor.

Gifts
Our team members are **not** allowed to accept gifts of any kind from patients and their families.
Team Members
Team Members

The feeding disorders program involves team members from different areas of expertise in taking care of patients.

- Pediatrician (pe-de-a-trish an) – this is a doctor who specializes in the treatment of children’s disease.
- Gastroenterologist (gas tro-en ter-ol o jist) – this is a doctor who specializes in illnesses of the stomach.
- Clinical psychologist – this person works with the patient to treat their mental, emotional, or behavioral illness.
- Nurse – this person is trained to assess your vital signs (temperature, heart rate, breathing rate, and blood pressure). He/she will take care of your physical needs. The nurse will also set up your follow-up appointments.
- Dietician – (di-e-tish an) – this person is trained in nutrition
- Occupational Therapists – this person will develop a plan to help you maintain your skills for daily living and work.
- Speech and Language Therapists – this person works with you on your:
  - Speech
  - Language
  - Communication skills
  - Other problems
    - Swallowing
    - Drinking
    - Eating
- Behavioral Analysts – provides behavior analytic services to the different populations.
- Behavioral Technician – this person works with the behavior analysts to help with:
  - Preparing meals
  - Recording data
  - Other needed tasks
Approach to Care

Behavioral feeding sessions are different from traditional speech therapy sessions.
- Speech feeding – focuses on oral motor skill deficits and disorders.
- Behavioral feeding – focuses on behavior problems that impact feedings.

Applied behavior analysis is used to guide all assessment and treatment decisions.
- Focuses on the “why” the behavior happens.
- Directly treats the associated causes.

The behavioral feeding sessions are designed to assess and treat the problem behaviors based on the causes of the behaviors.
- Providers will assess antecedents (these are events that happened before the behavior) and consequences that make the behaviors happen. Examples of this may be:
  - Observing family meals to see if the parent’s attention may lead to increased food refusal.
  - Providing an item the child likes after accepting something they do not like. We are looking to see if this may lead to more acceptances of foods the child does not like.

After the assessment is completed, a function-based treatment plan is created. This treatment plan often includes, but is not limited to:
- **Behavior management strategies**
  - This technique is used to help teach your child how to act appropriately.
- **Extinction procedures**
  - This technique is used to remove challenging behaviors your child may have.
- **Reinforcement procedures**
  - This technique is used to increase the desired behavior for your child.
- **Shaping behaviors**
  - This technique is used to teach the patient the desired behavior. It is done by working through a series of actions until the desired behavior happens.
- **Exposure activities**
  - This technique by having your child exposed to different stimuli over and over again. This may cause challenging behaviors to happen. Over time, this will help to decrease those challenging behaviors.

After a successful treatment is found, parents are trained in using the treatment during feeding sessions.
Your child will have 3 or 4 therapeutic feeding sessions each day. The feeding sessions will be based on an individualized treatment plan created for your child.

- A behavioral analyst will be in charge of your child’s feeding session.
- Often a psychologist will help with the feeding session.
- Your child will be evaluated by our pediatrician at least 1 time each week.
- A dietician will meet with you and your child at least 1 time each week. She/he will evaluate your child’s progress toward their nutritional treatment goals.
What to Expect

Evaluation
The evaluation process starts with a referral by your child’s doctor. When the referral is received:

• Your child’s medical records will be reviewed.
• You will be contacted by phone for a short interview.
• A complete evaluation will be scheduled with our assessment team.

Assessment
Our team will assess your child during their clinic visit. You will need to plan **1 to 2 hours** for the assessment. During this time we will try to observe your child eat. You will need to bring these foods for your child to the clinic visit:

• 1-2 kinds of foods that your child normally will eat.
• 1-2 kinds of foods that you have trouble getting your child to eat.
• If your child is not taking any foods by mouth, bring the tube-fed formula you use if you will need to start a feeding during the appointment time.

Assessment process

• Talk with you and your child.
• Review of your child’s medical record. This will include your child’s growth and current medical problems.
• Physical exam for your child.
• Nutrition history and evaluation of nutritional limits.
• Psychological assessment of how your child does in their:
  o Cognitive (thinking) ability
  o Emotions
  o Behavior
• Oral motor skills (self-feeding skills) assessment
• Fine motor skills related to their feeding skills assessment
• Observation of a pretend meal/snack time
• Psychosocial evaluation

Other tests
Other tests that may be ordered based on the initial evaluation.

• Video swallowing study
• Upper GI
• Gastric (stomach) emptying study
• Allergy testing
After your child’s assessment is completed, the feeding disorder team will meet to review the assessment. We will meet with you to talk about the right treatment choices for your child. These treatment choices may include:

- Partial hospitalization
- Outpatient treatment – this may include:
  - Psychologist
  - Occupational Therapy
  - Speech Therapy

If your child is recommended to take part in the feeding program, Sanford Health will start the pre-authorization process. If you receive approval from your insurance company:

- Your child will be scheduled into the recommended program based on their evaluation.
- You will be sent a packet of information for you to review and complete the needed forms.

**Goal Setting**
Goals for your child will be talked about and set at the beginning of treatment. These goals can be changed during treatment. These goals will be reviewed at the time of discharge.

**Your Child’s First Visit**
- There will be more evaluations with your child’s treatment team. This will help the team decided what is the best course of treatment.
- The treatment team will observe meals fed by the parent/caregiver.
- The treatment team will assess your child’s feeding problems.
- After the first assessment, your child will have 3 to 4 therapeutic feeding sessions each day.
- An individual treatment plan will be created for your child. This is based on the results of your child’s evaluation.

**What you need to know**
Most often when a treatment begins, a child’s challenging behaviors such as crying and refusal to eat, *increase greatly*. These behaviors will decrease with consistent and accurate feeding treatments. If you have any questions or concerns about your child’s treatment plan, please talk with your child’s psychologist.
The Parent's Role
The Parent’s Role

As your child’s parent/caregiver, you are a very important part of our team and your child’s treatment plan.

During your child’s admission, you will learn about:
• The reason for the interventions we use.
• How to support and maintain the progress made toward the treatment goals.

You must be here with your child at all times during the treatment. Reasons for this:
• To complete assessments of your child.
• Training
• Be a support person for your child.
• Some insurance plans require this for coverage. You will need to check with your insurance about this.

When a treatment plan has been created for your child, and your child begins to make progress towards the treatment goals, parent/caregiver training will happen. You will learn to:
• Help your child develop feeding behavior that can be maintained in:
  o Your home
  o Community environments
• Implement the treatment protocol in a variety of different settings with the supervision of a feeding therapist.

You may include others in your family who you would like to be trained.

Things to know
• Your child must be supervised at all times when they are not in a treatment session.
• Arrive on time to your child’s feeding session.
• If your child is sick, or you will be late, you must call your child’s therapist.
  o Phone Number ________________________________
• Sessions will be stopped if your child is:
  o Always late for meals.
  o Missing scheduled appointments.
Discharge

Before your child is discharged from the treatment program, the goals created for your child during treatment should be met.

Your child will be given:

• A detailed written plan to be used by anyone who will be feeding your child
• A training video may be given to you. This can be used to show the techniques and strategies that were used during treatment.
  o It is important that others use these same techniques so your child can learn what is expected during meals.

The paperwork that was completed at the time of admission will need to be filled out at discharge. This is used to look at and compare your child’s progress at the beginning and end of treatment.
Follow-Up Care

You and your child will need to have a follow-up appointment 2 weeks after discharge. During this appointment:

- Our staff will have a meal with your child. We will evaluate the results of treatment.
- Recommendations for continued follow-up care will be based on the results of this visit.

If you have any questions before your child’s follow-up appointment, you can call your child’s psychologist.

If you are not able to attend the follow-up appointment, talk with your child’s psychologist about how you can get help with any needs your child may have related to his/her feedings.
My Questions
My Questions
My Journal
My Journal