Family-Centered Care: Assisting Decision-Making to Proceed with Gastrostomy Placement for Nonoral Feedings

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**Background/Objectives:**
- To describe family-centered care used when a child with cerebral palsy or other developmental disabilities is unable to continue with oral feedings to meet their nutritional needs.
- To describe an interdisciplinary approach to assist families in shared decision making when they are considering whether or not to proceed with gastrostomy placement.
- To explain post-gastrostomy placement education and discharge teaching provided to families/caregivers by an interdisciplinary team at a pediatric orthopedic hospital.

**Reasons for Gastrostomy Placement may Include:**
- Dysphagia
- Significant decelerations in growth velocity due to inadequate intake
- Unable to consume adequate fluids to maintain hydration
- Multiple episodes of pneumonia

The physician or other interdisciplinary team member may initiate a discussion with the family/caregivers about gastrostomy placement for the child. **The decision can be complex for many families, as emotional, cultural, social, and financial factors all need to be considered and incorporated into the plan of care.**

**Steps for Gastrostomy Placement:**
- **Pre-surgical testing (as indicated):**
  - Upper GI imaging
  - Nuclear medicine gastric emptying
  - Nutritional labs
  - RN / APN / and social worker
  - Coordinate testing and referral to the pediatric surgeon.
  - Communicate testing and consult results with the interdisciplinary team for review and discussion.
- **Surgery is scheduled:**
  - The pediatric surgeon’s office notifies the interdisciplinary team of the surgery date.
- **Postoperative admission** is coordinated by the RN/APN for gastrostomy teaching and feeding implementation.
  - RDN consulted for Medical Nutrition Therapy for enteral feedings.
  - Social worker consulted to assess for funding sources and a medical supply vendor.
  - RDN completes and submits the necessary paperwork for insurance/Medicaid/other funding source approval. Enteral feeding supplies and formula will be delivered, either on the inpatient unit or upon discharge home, to ensure continuity of enteral feedings.

**Process:**
Information is provided by an inter-disciplinary team in a family-centered manner to assist with decision making to ensure quality of life for the child.
- Physician (MD)
- Registered Dietitian Nutritionist (RDN)
- Nurse coordinator (RN)
- Social worker
- Pre-surgical education with a “show and tell” kit allows the family to see what enteral feeding supplies look like and to have a hands on experience with various gastrostomy/low-profile gastrostomy buttons, extension sets, and other enteral feeding equipment.
- The RDN demonstrates an enteral feeding, and discusses possible enteral feeding regimens and schedules. Some children combine oral and nonoral feedings. Child Life may be consulted to engage the child in the discussion.

**Admission Post-Gastrostomy Placement:**
- Interdisciplinary team works with the family to implement enteral feedings.
- RN/APN and MD follow up with any postoperative medical needs the child may have, such as constipation, pain, or stoma site problems.
- RDN determines the type of enteral formula to use and initiates enteral feedings.
  - Based on the child’s tolerance to enteral feedings and a home schedule is developed by the RDN that is family friendly and ensures the child is meeting their nutritional needs.
  - School and/or home nursing orders are provided to ensure continuity of enteral feedings.
- RN provides hands on teaching for families on how to care for the gastrostomy/low-profile gastrostomy button, implement enteral feedings, and troubleshoot feeding problems.
- A follow up clinic visit is scheduled within two weeks of discharge to evaluate growth and enteral feeding regimen tolerance.

**Significance:** The decision to proceed with gastrostomy placement is difficult for many families to make. A family-centered, interdisciplinary approach ensures families are prepared for the gastrostomy surgery and able to implement an enteral feeding regimen upon discharge.

**Reference:**

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