When a sick child won't—or can't—eat

By Lynn Singer, PhD

Children with chronic diseases or developmental disabilities often develop serious feeding problems. This article explains why these children are vulnerable and how behavioral therapy can help.

At one time or another, all parents are concerned about the way their children eat—or refuse to eat. These problems are usually transient in healthy children, but they may persist in children who are seriously ill or developmentally disabled. Some feeding problems are so serious that they retard growth, exacerbate symptoms, and threaten normal social and emotional development.

Until recently, eating and feeding disorders in developmentally disabled and medically ill infants and young children received little attention. This oversight is surprising, given the emphasis on feeding in general pediatric practice. During infancy, disturbances in eating can have a profound effect on general health, growth, and development. Children with developmental disabilities often need intervention starting early in life to promote normal feeding patterns and combat the problems caused by neuromuscular or other structural abnormalities. Parents of children with severe developmental disabilities need anticipatory guidance about feeding-related difficulties.

Feeding problems often have devastating psychological impacts on the child and family. For all of these reasons, feeding problems warrant the attention and involvement of the pediatrician. This article will review the genesis of feeding problems in children at risk and offer strategies for helping parents. In many instances, successful intervention will require involving colleagues from other disciplines who can provide behavioral therapy.

What is a feeding problem, and who has one?

Feeding problems have been defined as the inability or refusal to eat certain foods because of neuromuscular dysfunction, obstructive lesions, psychological factors, or a combination of these. About 25% of children have feeding problems for which their parents seek professional help. Researchers estimate that 1% to 2% of all infants and children demonstrate feeding problems severe enough to retard growth.

Parents of children with developmental disabilities are more likely than other parents to seek help with feeding problems; approximately 33% of them do so. Although such children often need intervention to develop normal feeding patterns, research suggests that parents do not always get the anticipatory guidance they need, even when disabilities are severe.

The prevalence of feeding problems in infants and young children with chronic illnesses has not been established, but case reports indicate that medical illness is a risk factor for eating difficulties. Feeding problems may, in fact, be underreported in medically ill children, because growth failure may be attributed to the underlying illness.

Why feeding goes wrong

A variety of factors can predispose a child to a feeding problem...
or cause one to persist (Table 1). Intrinsic factors in the child, such as prematurity, illness, neurologic disorders, and structural malformations, as well as factors in the child's environment, such as parental stress, depression, or family instability, interact to create childhood feeding disorders (See the case histories on pages 64 and 65).

In the healthy infant, feeding is regularly and consistently paired with feelings of satiety, pleasure, security, and relaxation. The baby learns to associate feeding with these pleasant experiences and eats well. In the infant with chronic or acute illness, this pattern of associations may be disrupted. Feeding may be associated with painful oral intrusions (e.g., from a nasogastric tube), separation from parents, abdominal cramping, gagging, vomiting, and bad-tasting medications. These unpleasant sensations may lead the infant to avoid eating particular foods or to reject the feeding experience altogether, especially if the strength and regularity of his appetite have not been well established. Some researchers consider these avoidance behaviors "phobic" responses to the presentation of food.

In children who have had unpleasant feeding experiences, gagging, vomiting, or crying can easily become conditioned responses to food. Because there is some evidence that visceral responses are highly susceptible to Pavlovian conditioning, illness that involves gastrointestinal distress is a particularly powerful stimulus for aversive responses. Some researchers believe that extensive negative experiences with food and deprivation of normal feeding experiences are particularly critical during the first 18 months of life.

Parental reactions can either maintain or diminish the feeding response. When parents respond to an infant who refuses to eat by force-feeding, coaxing, giving increased attention, removing the child from the feeding situation, or substituting dessert or preferred foods, they often reinforce the child's avoidance of food, particu-
larly since these responses tend to be applied inconsistently.6-7,9

If the child is, or has been, seriously ill, many parents find it especially difficult to set reasonable limits on feeding. More than 25 years ago, Green and Solnit described the “vulnerable child syndrome,” suggesting that the experience of a severe acute or chronic illness can alter the parent-child relationship.11 Their observations have been borne out in recent studies. For example, mothers of premature infants stimulate their babies during feeding more than mothers of full-term infants do, apparently to compensate for the infants’ slower and less active responses.14 Parents of chronically ill children often feel depressed, and doubt their competence as parents.15–16 In my own work with children with cystic fibrosis (CF), I have seen a number of instances in which eating behavior is out of control. The mothers tell me they feel unable to limit their child’s behavior because they are afraid the child will die.7

**Children at risk**

Children with developmental disabilities such as cerebral palsy, Down syndrome, or autism, or congenital anomalies such as cleft lip and palate or myelodysplasia, often have structural, neuromuscular, and learning abnormalities that interfere with the mechanics of eating. Impaired coordination of sucking and swallowing may make nursing difficult, or the intricate neuromuscular control required for breathing, chewing, and swallowing solids may be compromised or delayed. The developmentally disabled child may have abnormal oral-motor patterns, muscle tone abnormalities, irregular breathing patterns, or impaired tactile sensitivity, all of which can make learning to eat difficult. Feeding is slow and oral intake poor. Children with these types of problems may present with a hyper- or hypoactive gag reflex, reduced tongue or cheek control, delayed oral or pharyngeal transit times, delayed or absent swallow reflex, pharyngeal dysmotility, reduced pharyngeal closure, aspiration, or cricopharyngeal spasm.17

Occupational therapists often recommend special positioning to facilitate feeding in these children, and use techniques of oral desensitization and sensory education to address mechanical feeding problems based on the individual diagnosis. They are also knowledgeable about prosthetic devices, special nipples, and specially adapted feeding equipment such as spoons and high chairs.

Children who have mechanical feeding problems are likely to develop maladaptive eating behavior unless preventive therapy is initiated very early. About 40% of children with cleft palate, for example, continue to have conditioned dysphagia even after the defect has been corrected with pharyngeal flap surgery.18 Many parents of children born with esophageal atresia encounter feeding problems for years, even though the defect is surgically corrected soon after birth.4 Learning problems can also lead to feeding difficulties, when delays in the acquisition of self-feeding skills make mealtimes slow and burdensome for parents.

Psychologists at the Kennedy Institute for Handicapped Children in Baltimore have documented the health-impairing severity of maladaptive feeding behaviors in many severely disabled children. Their pioneering use of be-

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**TABLE 1**

**Predisposing factors for feeding problems**

<table>
<thead>
<tr>
<th>Neurologic problems</th>
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<tr>
<td>Mental retardation</td>
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<td>Hyperactive gag reflex</td>
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<tr>
<td>Long-term tube or intravenous drip feedings</td>
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<tr>
<td>Larger-than-normal caloric requirements</td>
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<tr>
<td>Parental stress and depression</td>
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<tr>
<td>Vulnerable child syndrome</td>
</tr>
<tr>
<td>Chronic medical problems</td>
</tr>
<tr>
<td>Difficult temperament</td>
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<tr>
<td>Decreased social responsivity</td>
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<td>Prematurity and low birth weight</td>
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Behavioral solutions to eating problems: Two case histories

Melissa
Melissa was diagnosed with cystic fibrosis (CF) at 10 weeks of age. At 21 months—when she was admitted to the hospital with cough, congestion, intermittent fever, and fatigue—she was below the fifth percentile in height and weight and taking in only about 56% of the calories she needed. The pediatric pulmonologist and the gastroenterologist who examined her recommended parenteral feeding, via a gastroesophageal tube. They also referred the family to the hospital’s feeding team, which included a pediatric psychologist, a nurse, a dietitian, and an occupational therapist.

The team found that, although Melissa wasn’t eating enough or growing well, she was otherwise developmentally normal with oral-motor and feeding skills appropriate for her age. Her CF was well managed, and her feeding problems were not the result of a biological limitation. What, then, was causing them?

Watching Melissa at mealtimes provided the answer. She would not stay in her chair. She shook her head and said “No” as soon as food was offered, she would cry, her mother would try to coax her to eat a portion of food; and Melissa would gain and ventriculoperitoneal shunt to the meal, and for the rest of the day Melissa’s mother would follow her around, offering her a banana and cookies.

Melissa’s mother was afraid to sell missiles on her daughter. She could not bear to see her child unhappy, she told the therapist because she was afraid Melissa was going to die. Discussions over how to handle Melissa had put stress on their marriage as well.

The mother needed to understand that the eating pattern she permitted was endangering her daughter’s life and that the way to safeguard Melissa was to help her learn to eat normally. Initially, Melissa’s gagging and crying were related to her illness, the therapist explained. When Melissa discovered that her behavior gained attention and put her in the driver’s seat, she kept it up, and she would continue to do so until her mother changed the way she dealt with mealtimes. Melissa’s mother also needed “how-to” instructions. The therapist told her to expect Melissa to eat only a very small portion—perhaps just one mouthful—at first. She was to put the portion in front of Melissa, prompt her to “take a bite” once, and then ignore her. If Melissa ate, she received praise and a gold star. At the next meal, Melissa’s mother could offer a slightly larger portion, but the increase had to be very gradual.

After 11 days of this new mealtine routine, Melissa was discharged from the hospital. Her food intake had increased to 100% of her needs during hospitalization, and the progress was notional home. By the time Melissa was 4 years old, she was back on the growth curve; her weight looked the 25th percentile.

Max
Three-year-old Max was referred to the feeding team by the pediatric gastroenterologist who had been treating him since birth. Max had become more and more restrictive, and in the weeks preceding the referral, he had eaten very little. The therapist Max’s mother had

Behavioral treatment to promote normal eating patterns has been successful in changing these maladaptive behaviors and reversing growth failure. (See the box on page 68).

The chronic illnesses most commonly associated with feeding problems are congenital heart disease, CF, phenylketonuria (PKU) and other metabolic disorders, cancer, diabetes mellitus, asthma, bronchopulmonary dysplasia (BPD), and acute gastroenteritis (Table 2). Children with cerebral palsy, a history of very low birth weight or tube-feeding, and those with cleft lip and palate or other malformations are also at high risk.

Table 3 lists factors often present in these chronic illnesses that can be associated with feeding problems. Children with CF, can-
been keeping showed that his total intake was only about 350 calories a day with almost no protein. He was living on cookies, crackers, and grape juice, and—since the day he’d witnessed a serious kitchen fire—would eat only in the basement.

Max had had a difficult start in life, full of medical problems that were closely connected with food and eating. He had been colicky, received cimetidine for esophagitis, suffered from a gastrointestinal virus, was put on a protein hydrolysate formula for a time, and developed a severe GI reaction to antibiotic treatment for otitis. He had also been diagnosed as lactose intolerant and kept on a milk-free diet. At 18 months, once more allowed to drink milk, he ate a rather restricted diet but took in enough food to grow reasonably well.

He continued to find eating difficult; however. He choked and gagged and threw up during meals, at a rate of two or three times per week. When he choked on a particular food—even a former favorite, like chicken nuggets—he refused to try it again. He ate fruit and vegetables only in pureed form and ate well only when he was offered baby food. He had a favorite cup with a spout and refused to drink from any other container.

As Max’s eating deteriorated, his parents became increasingly concerned. They threatened him with punishment when he wouldn’t eat, and they tried to force-feed him. Max’s reaction was to reduce his limited intake of solid food even further. Yet despite this conflict over eating, neither Max nor his parents had any serious, underlying psychologic problems. They were willing to come to therapy sessions to talk about the importance of normal eating and to take part in behavioral therapy designed to change Max’s eating patterns.

Therapy began with high-calorie milk shakes. Max was expected to drink a quarter of a cup every hour. If he did that, he was praised, given a sticker as a reward, and allowed to have cookies and crackers. If Max were like most patients, this reward program would have been sufficient. But because Max’s caloric intake was so severely limited, he was also put in time-out for 15 minutes as a penalty whenever he refused to drink. As Max began to go along with the program, the expectations for how much he was to drink were gradually increased to a whole cup at a time, at longer intervals.

Max was expected to increase his intake of solid food as well, starting with choices he made in the therapist’s office with his parents. On the therapist’s advice, Max’s parents simply told him he couldn’t have his meals in the basement any longer. From then on, he ate where the rest of the family ate. Whole fruits and vegetables were gradually added to his diet. When those goals were met, new goals were set: drinking from an ordinary cup, eating at preschool, eating in a restaurant. Max had no episodes of choking or gagging while he was in therapy. After six months, his diet was essentially normal and his eating skills were appropriate for his age.

cer, or BPD have unusually high energy requirements. They may need up to 50% more calories than the norm for a child the same age. Yet fatigue and anorexia due to chemotherapy, infection, or pain make it difficult for these children to take in all the calories they need. Infants with BPD find it difficult to breathe while feeding; they show a higher incidence of oxygen desaturations during feedings that may account, in part, for their difficulties. 20

Dietary restrictions in PKU or other metabolic disorders, rigid meal schedules for diabetic children, or unpleasant dietary supplements for CF may adversely affect eating. The need to ingest unpleasant-tasting medications can create additional problems at mealtimes. Children who have had a severe GI illness marked by
TABLE 2
Look for feeding problems with these conditions

<table>
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<tr>
<th>Condition</th>
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<tr>
<td>Congenital heart disease</td>
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<tr>
<td>Cystic fibrosis</td>
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<tr>
<td>Phenylketonuria and other metabolic disorders</td>
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<td>Cancers such as acute lymphocytic leukemia</td>
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<td>Diabetes mellitus</td>
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<tr>
<td>Asthma</td>
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<tr>
<td>Gastrointestinal disorders</td>
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<td>Inflammatory bowel disease</td>
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<tr>
<td>Esophagitis</td>
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<tr>
<td>Acute gastroenteritis</td>
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<tr>
<td>Irritable bowel syndrome</td>
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<tr>
<td>Encopresis</td>
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<tr>
<td>Gastroesophageal reflux</td>
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<tr>
<td>Bronchopulmonary dysplasia</td>
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<tr>
<td>Cerebral palsy</td>
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<tr>
<td>Gastrostomy</td>
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<tr>
<td>History of tube feeding</td>
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<tr>
<td>Cleft lip and palate</td>
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<tr>
<td>Down syndrome, autism, spina bifida, myelodysplasia</td>
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TABLE 3
How illness can lead to feeding problems

<table>
<thead>
<tr>
<th>Illness</th>
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<tr>
<td>Altered energy and nutrient needs</td>
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<tr>
<td>Fatigue</td>
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<td>Mouth sores</td>
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<td>Constipation or diarrhea</td>
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<tr>
<td>Food allergies</td>
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<tr>
<td>Dietary restrictions</td>
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<tr>
<td>Malabsorption</td>
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<tr>
<td>Drug interactions with food</td>
</tr>
<tr>
<td>Poor appetite</td>
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<tr>
<td>Delay in acquiring feeding skills</td>
</tr>
<tr>
<td>Nausea</td>
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<tr>
<td>Painful experiences of oral intubations</td>
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<tr>
<td>Lack of normal oral experiences</td>
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nausea, vomiting, and diarrhea may develop a conditioned aversion to specific foods they were eating when they became ill. If symptoms are chronic or severe, the aversion may be generalized to the entire process of eating. Likewise, children with cancer who are on chemotherapy that produces nausea and vomiting may develop an aversion to particular foods or to eating in general. If after a number of chemotherapy sessions, some children feel nauseated and start to vomit even before treatment begins.

Infants with medical conditions that require gavage or parenteral feeding do not have the opportunity to practice the lip, jaw, tongue, and pharyngeal movements that are necessary for learning to suck, chew, and swallow. Infants who have been maintained on continuous drip feedings may not develop normal hunger-satiety cycles associated with feeding and do not have experience with the varied tastes and consistencies of food.

Helping parents cope

What can pediatricians do to help parents cope with feeding problems? Anticipatory guidance is crucial for parents of children born with conditions that are known to predispose to feeding difficulties. Knowing what to expect is half the battle when a child is going through a series of surgeries to correct a facial cleft, or is finally home from the hospital after many weeks of tube-feeding in the neonatal intensive care unit. The parents need long-term support, practical advice, and—at times—referral to colleagues specializing in nutrition, dentistry, speech, and occupational and behavioral therapy.

You can help parents define the nature and extent of a feeding problem in terms of growth and particular symptoms (See the list of key questions to ask in Table 4). Use the National Center for Health Statistics charts to plot growth data for children born at term and specially designed charts for preterm infants, often available through formula companies or the neonatology departments of large teaching hospitals. The child whose weight for height falls below the fifth percentile is probably malnourished. The most readily apparent indicators of a feeding disorder in a child with
chronic illness is weight loss or failure to maintain position on the standard growth curves despite adequate medical management of the primary disease.

When growth is retarded in medically ill children even after the illness is stabilized, consider behavioral factors. A feeding evaluation may eliminate unneeded laboratory tests. Growth failure is not "either" psychologic "or" medical; it is often both.6

When the charts show growth within normal ranges but parents are still concerned, encourage them to keep a record of what the child eats for a full week before the next appointment. The diary will highlight a seriously low caloric intake or a specific dietary deficiency, if one exists. If growth is normal and intake seems adequate, ask about mealtime routines. The parents’ responses may reveal the source of the problem.

You can assure parents of healthy, growing children that missing an occasional meal or refusing to eat a specific food does no lasting harm. Advise them to provide regularly scheduled, nutritious meals and snacks and to refrain from coaxing or begging children to eat. It is important to avoid struggles over eating. Your guidance and support will help diminish their concern and the tension and force-feeding that may accompany it—a good way to prevent real growth problems from getting started. An excellent book to help parents with garden-

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Working with the child who won’t eat

The techniques of behavior therapy are particularly helpful with children whose eating patterns are abnormal—even if the children have severe disabilities. Although therapy must be individualized, three basic approaches are used:

**Shaping**, or rewarding the child for achieving closer and closer approximations of the desired eating response. A child who refuses even to come to the table, for example, is rewarded at first simply for sitting in his chair for a brief period. Then he is rewarded for sitting calmly when a bit of food is put on his plate. Once he tolerates that, he is rewarded for tasting, then for swallowing, and so on, until he sits at the family dinette table and eats a reasonable meal.

**Ignoring**, or not reacting, verbally or otherwise, to the child’s protests, cries, and attempts to avoid eating. When the child realizes that his behavior doesn’t get a reaction, very often the protests are gradually reduced and eventually abandoned.

**Time-out**, or removing the child from the rewards of social interaction whenever his eating behavior is unacceptable. A child who screams or throws food, for example, may have his chair turned so that he faces away from the parent who is feeding him. If that is ineffective, he may need time-out in another room, without company or entertainment. At the end of a stated time period, he may return to the social world and be with people as long as his mealtime behavior is acceptable.

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variety feeding problems is Ellyn Satter’s *How to Get Your Kid To Eat . . . But Not Too Much.*14

**Evaluating feeding problems**

A thorough medical evaluation is warranted when feeding problems hamper growth, the child’s diet is inadequate, or potentially dangerous gagging, vomiting, choking or esophageal reflux occur. A number of signs, symptoms, or illnesses may point to a feeding difficulty secondary to neuromuscular pathology.17 These include frequent choking, gagging, or vomiting, thrust tongue, gurgling respiration, and frequent upper respiratory infections or recurrent pneumonia.

Assessment of oral-motor skills, evaluation of tactile sensi-
### TABLE 4

#### 6 questions that may unravel a feeding problem

1. **How long do meals take? Less than 10 minutes? More than 30?**
   
   *Very short or very prolonged meals may signal behavioral feeding problems.*

2. **Who feeds the child? Does he eat more with one parent feeding than he does with the other? How does he eat when the baby-sitter feeds him?**
   
   *Answers to these questions may offer clues to parent-child conflicts that are being expressed in eating behavior.*

3. **Where does the child eat?**
   
   *Feedings in the living room, TV room, or on the floor frequently reflect a degree of family disorganization or parental attempts to coax the child to eat.*

4. **How often does the child eat?**
   
   *Some parents “don’t have the time” to feed the child on a regular schedule. Others allow the child to eat continuously, so that he never feels the hunger cues that signal meal times. Either pattern is destructive of regular eating habits.*

5. **Does the child vomit, gag, spit up, leave the table, cry, have tantrums, refuse to eat at regular meals or when his parents prompt him to eat?**
   
   *These may be signs of psychological feeding problems.*

6. **What do the parents do when the child puts up a fuss at meals?**
   
   *Some parents allow the child to leave the table or acquiesce to all of his food quirks, however restrictive. Others punish this kind of behavior or try to force-feed the child. If you know how parents habitually respond, you can tailor your advice accordingly.*

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- Activity, and video fluoroscopy of swallowing mechanisms are basic components of the medical evaluation. A modified barium swallow can assess the child’s responses to various food consistencies, oral and pharyngeal transit times, and motility. It can also help evaluate conditions associated with aspiration. Oral skills and tactile sensitivity can be assessed by observing the child’s reaction to foods of varying types and consistencies. The pediatrician can make these assessments directly or in consultation with a psychologist, speech pathologist, or occupational therapist. In children with serious feeding problems, these assessments should be done frequently during the first two years of life.

For children with developmental disabilities, it is always important to coordinate an evaluation and treatment plan with occupational, physical, or speech therapists who are knowledgeable about feeding problems. I believe that most of these problems are preventable when pediatricians actively involve rehabilitation therapists in evaluating feeding as a developmental skill from birth. Many tertiary level pediatric hospitals, in fact, now have interdisciplinary “feeding teams” that include pediatricians, psychologists, dietitians, and rehabilitation therapists skilled at addressing the multiple needs of children who have developmental disabilities.

#### Dealing with behavior problems

Whatever the genesis, feeding disorders can be destructive of children’s health and family peace. Parents may ask for your help with children who cry or throw tantrums during meals, won’t open their mouths for food or pocket it in their cheeks, spit, gag, vomit, or throw food. Other signs that intervention may be needed include refusing to sit at
the table to eat, snacking on "junk" foods throughout the day, and having a short list of acceptable foods. Very lengthy or very short mealtimes, or lack of regular mealtimes, also signal a potential problem.

You may find that parents are reacting in ways that actually reinforce the behavior that concerns them. They may coax, threaten, force-feed, punish, or simply give up—allowing the child to eat anything he wants, whenever he wants. I have seen a 5-year-old who ate nothing but soft, white, mushy food after an earlier, acute GI illness. His parents gave him special rewards for eating. I treated a 3-year-old recovering from surgery for a brain tumor who could not be weaned from his gastrostomy tube because the only foods he was willing to eat were potato chips and cookies; whenever his parents asked him to taste a food, he would scream until they let him get down from the table.

As a feeding therapist, I have found that guidance, reassurance, education, and support for parents' efforts to structure meals can begin to reverse such a negative cycle. I advise parents to begin by limiting the child's access to food apart from regular meals or planned snacks. I teach parents to "neutralize" feeding instead of overreacting and to keep track of when specific behaviors occur. These first steps give me time to assess the emotional climate in the family and gather information about parental anxiety or depres-
Seizures and Epilepsy in Childhood: A Guide for Parents

John M. Freeman, M.D., Eileen P. G. Vining, M.D., and Diana J. Pillas

Written by experts from the Pediatric Epilepsy Center at the Johns Hopkins Medical Institutions, this book provides the latest information about diagnosis, treatment, and the possible side effects of treatment for seizures and epilepsy. The authors, who are board members of the Epilepsy Foundation of America, present the facts and resources parents need to keep their children's seizures from becoming a handicap.

"Likely to become the essential 'Dr. Spock' for parents of a child with epilepsy."—Timothy A. Pedley, M.D., Columbia University

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Exp. /
Signature ________________________________
Name ________________________________
Address ________________________________
City ________________________________
State/Zip ________________________________

FEEDING DISORDERS

sion, significant psychological stressors (such as marital problems) that might warrant separate intervention, and parental ability to follow through with a program.

If these initial steps do not begin to resolve the feeding and growth problems, you may need to refer the family to a pediatric psychologist with expertise in behavioral treatment or feeding or to the feeding team at a pediatric hospital. If the child is significantly maldnourished, hospitalization may be warranted, especially if the parents are unable to change the way they deal with feeding difficulties.

Appropriate treatment for behavioral feeding problems entails assessing the behavior that interferes with eating and understanding the variety of psychological issues that influence the parent-child interaction. Therapy is based on consistent expectations for the child, a gradual increase in goals, appropriate rewards, the use of time-out, calming techniques, and gradual desensitization to feared or aversive foods.

Pediatricians who are knowledgeable about the role of psychologic and behavioral factors in feeding and growth disorders can assess these problems. intervene effectively, and refer when necessary.

REFERENCES

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