

Nutrition Care For Children

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Case Comparisons: Therapeutic Diets for Autism With and Without Amino Acid-Based Formulas (AABF)

Abstract: Children with autism spectrum disorders (ASD) often have rigid eating patterns, suboptimal growth patterns and/or gastrointestinal (GI) symptoms. Endoscopy (a procedure that shows inside the GI tract) has been used on several ASD children to screen for what may be causing these problems. Findings on endoscopy show that ASD children have inflammation, ulcers, lesions, and other problems in the esophagus, stomach, and intestine more often than normal. They also have reflux, diarrhea, constipation, abdominal pain, and bloating more often than normal. These case studies describe outcomes of dietary therapy for children with ASD and GI symptoms. Dietary therapy with AABF improved the child's nutritional status, GI symptoms, growth, and development more than same without AABF. These case reviews were requisitioned for consumer audiences in fall 2007 by Nutricia North America, maker of EO28, the formula used in these cases. The cases occurred from 2001-2004. No sponsorship for the use of formula was provided. For more information on these cases, contact Judy Converse at info@nutritioncare.net. © Judy Converse/Nutrition Care For Children, Boulder, CO 2008.

Case 1: Growth and Developmental Problems Resolved

The parents of a boy age 24 months with Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) self-referred to Nutrition Care. This was the family's second child. Clinical evaluations showed that he had gross and fine motor delays, toe walking, hypersensitivity to light and noise, low muscle tone, high joint mobility, and postural instability. He was also non-verbal but had some receptive language (understood what he heard). Tests for brain and gene abnormalities were normal. His history showed that he was born at nearly full term at a normal weight. The mom needed antibiotics in pregnancy but otherwise, there were no concerns. She needed them again while nursing. He took only breast milk for the first six months and was a strong feeder but was colicky. Mom noticed this worsened when she ate dairy products. She needed antibiotics once more while nursing. In infancy the baby began having constipation. By age 2, bowel movements occurred once every 4-7 days and tended to be explosive and watery, with both hard and mushy pieces passed. Laxatives were used if there was no bowel movement after 7 days. The first sign of developmental delays began when the boy was four months old and was unable to roll over. At about 18 months, the boy began developing language skills, which then lapsed, along with social behavior and smiling. Since birth the boy also had difficulty sleeping, typically waking up about three times per night.

Nutrition Findings:

During the consult, the child was unresponsive to his name, lacked eye contact and used garbled single words occasionally. He preferred to play alone and avoided other children. He walked in circles, returned to his mother often for brief nursing and showed poor balance and toe walking. Interaction with the nutritionist was avoided in favor of self-soothing behaviors such as rocking or flapping and there was not age appropriate exploring or playing. A food diary evaluated by the nutritionist showed that the boy's appetite was poor. The mother nursed him six times per day to help calm him. He usually ate about half of what he needed to grow and develop normally. He ate enough protein, but not enough total calories, so he was too thin for his height. His growth pattern also showed that he could not absorb protein well, because he was shorter than expected: He had dropped from 75th percentile at birth to 25th at this visit, for length for age. This growth pattern, in the context of an adequate protein intake, means that protein is not being absorbed normally. Other signs that protein was probably malabsorbed in this case were eczema rashes on cheeks and messy irritable stools. Food allergy testing (RAST for IgE) was negative. The nutritionist did further tests (ELISA for IgG), and this showed reactions to several foods. This explained many of the boy's symptoms and why he was growing and eating poorly. Celiac serology was negative. Though ELISA showed some inflammation triggered by gluten (wheat protein), casein (dairy protein), and many other foods, he did not have celiac disease. The boy's doctor also checked for metabolic disorders that may make muscles work poorly and keep energy level low. These tests were normal, but poor iron status was found. This was due both to marginal diet and difficulty absorbing nutrients. Stool microbiology suggested excessive *Candida* (yeast) and disruptive bacteria species, with a lack of beneficial flora.

Assessment/Plan:

At the time of initial consult the boy's total calorie intake was about half of what he needed for his age, weight, and growth status. Breast-feeding prevented him from eating enough solid foods. It was recommended that he start ongoing occupational and sensory integration therapy, so he could learn activities to organize and soothe himself

without breast feeding. The lab tests, growth pattern, and food diary showed malabsorption, inadequate diet, and entrenched growth regression (he had not been growing as expected for a long time). The malabsorption was caused by low-grade, chronic inflammation from several foods, including wheat and dairy, and worsened by overgrowth of yeast and disruptive bacteria in his gut. He needed to double his food intake, and use proteins that would not be inflammatory. He also needed to fix the gut yeast and bacteria. EO28 formula was chosen to replenish the boy's diet. This is a nutritionally complete elemental formula – the protein in it is ready to absorb and does not require digestion. All dairy, including breast milk, was removed, as well as gluten. The family was also instructed on how to increase their son's intake of solid foods. Helpful bowel flora (bacteria) was restored by using herbs, prescription antifungal medicine, and probiotics. A goal for calorie intake per day was set at 1200-1300 calories. This included 25-35g protein, 40-45g fats and the rest as carbohydrates. Dietary supplements included a teaspoon per day of cod liver oil, a high potency multivitamin for the B group, 100mg per day of co-enzyme Q10 and the daily recommended intake of supplemental minerals. Referrals were encouraged to gastroenterology and metabolic disorders specialists for continued monitoring.

Outcome:

Eight months after the initial consult, the boy had recovered a healthy growth pattern: He weighed 30 lbs (45th percentile for his age) and was 36.5 inches tall (45th percentile for his age). EO28 became an integral part of his daily nutrition routine. For the first time, the child was able to go through the winter season with no infections, consistent with improved protein status. Toe walking, circle walking and teetering off balance had stopped. The child was now sleeping through the night. Anxiety and irritability were markedly lower than at first consult. Vocabulary increased to roughly 50 words and there was eye contact. Constipation improved to a bowel movement every 2-3 days, and these were soft formed. Follow up stool culture showed *Rhodotorula* persisting, so the boy was referred back to a gastroenterologist for a Ketoconazole antifungal prescription, which is used to treat yeast infections.

At follow-up a year later, the boy had progressed further. He was able to maintain eye contact and return smiles. He also had expanded his vocabulary, increased his socialization efforts, and had less anxiety. During playtime he was imaginative, interested in exploring his environment, and was playing near other kids. He had learned colors and body parts, and could name them. At follow-up five years from the start of nutrition care, the child had typical expressive and conversational language and no longer met criteria for PDD-NOS diagnosis. The mother reported that he had friends, was an "extrovert", had no cavities to date (a sign of good mineral absorption and healthy immune function), and was learning to ride a bike and to ski. He was in a regular classroom with no aide, versus restricted placement. ELISA test findings were all normalized. A restricted diet was no longer needed and the boy was doing well. Heavy metals testing showed excessive lead which was treated with Chemet, a drug to help treat lead poisoning.

In this case, EO28 provided the boy with a steady source of complete, absorbable protein and adequate total calories, both critical to his improved development, growth, and ability to fight infection. He used it until entering first grade. This case illustrates that an elemental protein source in a high calorie formula can help improve nutrition status, as well as learning and developmental growth, among kids with ASD when used in addition to other therapies.

Case 2: Special Diet Without AABF and Antifungal Therapy: Lesser Progress

The parents of a boy age 3 years 3 months self-referred for help with implementing a gluten and casein free diet. At first consult, an autism diagnosis had recently been confirmed. The family had just begun the gluten and casein free diet. History included difficulty feeding, colic and reflux since infancy. Nutramigen, a casein hydrolysate formula, was used during infancy with mixed success. Reflux persisted while on Nutramigen such that Propulcid was needed, to speed up emptying of the stomach as well as the rate that food moves through the lower intestine. The child had already had eight courses of antibiotics for ear and upper respiratory infections by the time of the nutrition consult. He progressed normally until about 15 months, at which point he started falling behind on milestones. Stools changed to chronically loose. Food intake was self-limited to starchy foods and milk.

Nutrition Findings:

At first consult the boy had no expressive language (he was non-verbal), but receptive language was intact. He was affectionate and engaging with parents. He was at 75th percentile weight for age and 60th percentile height/age, so he was a bit short for his weight. This suggests adequate calories are eaten, but not enough protein, or that protein is not absorbed normally. Lab results found that the boy had signs of anemia. He had some urine polypeptides that were high, but they had not come from dietary gluten or casein. A test for gluten allergy (gliadin antibody test) was negative. A stool test showed excess amounts of two kinds of yeast in his gut, too much disruptive bacteria,

and not enough healthy gut bacteria. ELISA test was normal, so he did not have inflammation from foods. As his growth pattern suggested, his food diary showed that he ate enough total calories, but not enough protein. He mostly ate milk and French fries, a very poor diet that did not give enough minerals, vitamins, essential fats, or protein.

Assessment/Plan:

Protein intake, vitamin and mineral status, sources of fats/oils, and bowel flora needed correction. EO28 was recommended. Supplementation was begun for high potency multivitamin, additional zinc, magnesium, cod liver oil, iron, and flax oil. The family wanted to trial a gluten and casein free diet as well.

Outcome:

The child refused EO28. Since it was eschewed and he continued in a rigid eating pattern, he did not eat adequate high value protein for normal growth and development; what he did eat was showing signs of being poorly absorbed. Though he followed a gluten and casein free diet and used many supplements, it did not trigger expected growth, and triggered only marginally improved developmental outcome. Correcting the bowel flora aggressively and early may have increased acceptance and compliance with EO28. Since many medicines cannot be combined with Propulcid, it took the family a long time to get the antifungal medicine he needed for this. Eventually, the boy was able to use some antifungal medicine but not enough to completely correct bowel flora. By age 6 years 7 months, the boy's weight for age status had flattened. He weighed 38 pounds (5th percentile weight/age). Most of his calories were taken as simple carbohydrates and he continued to suffer from low protein intake. Some gains in language occurred on the gluten and casein free diet, but this stalled at echolalia (repetition of vocalizations made by another person) and verbal scripting. During the winter, the boy had frequent illness due to poor protein status. He needed antibiotics often, which worsened bowel flora (antibiotics kill helpful gut bacteria but not disruptive yeast) and absorption. Constipation became chronic enough to require Miralax, an over-the-counter laxative. Treatment with Diflucan, an antifungal medicine, allowed temporary improvement in appetite, constipation and reflux but these returned and persisted with each course of antibiotics. Recurring illness, secondary to poor nutrition status, interrupted the improvements and made progress slow.

By age 10 years 6 months the child had recovered progress for his weight at 74 lbs (65th percentile for his age) and was 54.5 inches tall (45th percentile for his age). This growth pattern implies that the boy was back to eating enough total calories, but he still had a low protein intake. In addition, progress for expressive language was limited. He was still scripting (repeating rote memorizations of conversations heard elsewhere, eg from movies and TV shows or songs).

A missing piece of the nutrition therapy was an adequate, highly absorbable protein source to fuel expected gains in height, improve infection-fighting, and provide amino acids for neurotransmitter needs. EO28 would have been valuable in this regard and would have helped maintain good nutrition status while improvements to digestion, absorption, and bowel flora continued. This case illustrates that a gluten and casein free diet without a proper protein source may place children at risk for chronic protein malnutrition. In addition, they may experience only marginal success with regard to expected functional/developmental improvement. Early, aggressive correction of disruptive bowel flora may enhance acceptance of EO28.

Case 3: Chronic Calorie Malnutrition Impedes Learning, Growth, Behavior

The parents of a boy age 9 years 7 months Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) and cerebral palsy self-referred their son for nutrition care. The boy had feeding difficulties since birth, including frequent spit up, hard colic, low oral tone, poor latching, and slow nursing. When the boy reached age one, he began having constipation and developed several ear infections. The antibiotic treatments for the ear infections triggered mixed irritable stool patterns even after the boy finished the medicine. At age five, an X-ray showed impacted fecal debris in his colon, and the boy was still having difficulty with potty training. When the boy's parents decided to begin dietary therapy, he was still wetting the bed and had incontinence at school. Other difficulties in school included falling asleep in class, difficulty writing/needing a scribe, oppositional behavior, irritability, poor focus, and poor stamina for work.

Nutrition Findings:

At the time of the initial consult, the boy, then 9, weighed 54.5 lbs (5th percentile for his age) and was 51 inches tall (10th percentile for his age). His body mass index (BMI) was 14. This is at the cut off for an acceptable BMI for a child; it means the boy was underweight for his height, to a degree that could affect his health. The boy was born at 50th percentile weight for age. At 15 months, he dropped to the 5th-10th percentiles and remained there. This

suggests he was not growing to genetic potential. A food diary showed that he was eating about 1300 calories a day, including 50g protein (16 percent), 220g carbohydrate (70 percent) and 20g fat (14 percent). For a 9 year old boy, this is enough protein, but not enough total calories, and too low an intake of fats/oils. At the time of consult, the boy's parents had already started a special diet. They withdrew cow's milk and replaced it with rice milk. Based on ELISA testing done previously, the parents had also removed gluten, casein, eggs, soy, almond and peanut from their son's diet. This left few sources of high value protein and fats/oils. They also were using several supplements, including megadose pyridoxine. The supplements provided high intakes for some vitamins and low intakes for some minerals including calcium, zinc, iron and selenium. The child often complained of hunger. His fingernails were cracked/peeling, his hair was thin and dull and his skin was pale. These are signs of poor protein status.

Assessment/Plan:

The child had poor nutrition status, growth regression, and a chronic low total calorie intake for his age, weight, and growth status. These are established triggers for cognitive problems, insomnia, lethargy, and irritability. His total daily protein intake was adequate but quality of protein was too poor to support tissue growth and function. This was evident by his weak nails, poor sleep, thin hair, and irritability. Total daily intake of fats was also low. He needed more fats and oils from healthier sources. A goal weight was set for 60 lbs by the boy's 10th birthday, which would place him in the 20th percentile for his age. Calories were increased 100 kcal/kg (about 50 calories per pound) or 2300 kcal/day, or as near this goal as the family could achieve. To help with this goal, Nutrition Care For Children created a new menu and added snack items. Pepdite (a soy hydrolysate formula) and EO28 were both used successfully to increase quality of protein and total calories. Pepdite was tolerated well in spite of some reactivity on ELISA to soy protein. EO28 drink boxes worked well at school to increase quantity and quality of protein intake and provide calories otherwise lacking during the day. The parents worked with school staff to arrange additional time for snacks. Dietary restrictions were relaxed, allowing the parents to rotate almond and egg into their son's diet. Supplements were adjusted with a lower dose of Vitamin B6, 50mg chewable/day of Co-Enzyme Q10 (a supplement that helps the body produce energy), 200-400mg calcium citrate, up to 200mg magnesium/day and 1-2g omega 3 fatty acids/day. The nutritional formulas provided about 300-500 mg/day of calcium.

Outcome:

Five months later, the child had reached a weight of 59 lbs (15th-20th percentile for his age) and a height of 52.5 inches (22nd percentile for his age). His BMI was 15.1, much improved. He was recovering good growth and nutrition status. Reports from family and school providers showed that his sleep improved, and he no longer wet the bed. Incontinence at school had resolved within one week of getting an adequate diet. He showed more initiative, independence, clearer speech, increased vocabulary, greater use of sentences rather than fragments or phrases, neater writing, and less need for a scribe at school. Attention and focus at school still remained a challenge. Pepdite and EO28, which were no longer needed after one year, were critical to improving this child's total food intake. In addition to significant nutritional status improvement, the boy also showed gains developmentally, verbally, functionally, and for academic tasks.

Case 4: Improvement for Autism in the Context of Multiple Food Anaphylaxis

A family of a boy diagnosed with autism, aged 2 years 5 months, self-referred for nutrition care. He had been tested previously for food allergy (RAST) and food intolerances (ELISA). Both identified several foods that triggered inflammation. He had reflux and chronic diarrhea. He had tried several medicines for these unsuccessfully. His history included multiple infections and antibiotic treatments; hospitalizations for severe allergy reactions; asthma, eczema, and anemia. He had endoscopy, which confirmed damage from reflux in his esophagus, and eosinophilic infiltration in small intestine tissue (a sign of chronic inflammation). He had feeding difficulties since infancy. The pregnancy and birth were normal and this was the family's fourth child. His siblings had no history of these problems. Based on the positive ELISA and RAST findings, at time of the first nutrition visit, the parents had already eliminated dairy foods, gluten, bananas, apples, lentils, beef, fish, chicken, soy, tomatoes, pears, almonds and celery from their son's diet. Eggs, peanuts and walnuts could trigger a severe, life-threatening allergic reaction. Due to low muscle tone, the boy had undergone testing for metabolic disease, a condition that prevents normal energy production in muscle cells.

Nutrition Findings:

At time of initial consult the boy weighed 35 lbs (above the 90th percentile for his weight for age) and was 36 inches tall (50th percentile for his height for age; above the 90th percentile for his weight for height). This means he ate enough total calories but did not eat enough protein, or did not absorb enough protein. The boy's food intake was 900 calories/day, including 10g protein, 20g fat, and 170g carbohydrate. This is a lower intake than normal for a child at this age. Rice was the only protein source, which does not provide all the amino acids humans must eat to

grow and live. The family was supplementing him with high dose B vitamins, calcium, and probiotics. Medications for asthma and reflux were used daily. Albuterol, a medicine for wheezing and difficulty breathing, was used as needed. A stool test showed too much Candida (yeast) growing in his gut, as well as several types of bacteria that could trigger diarrhea. Thanks to the probiotic supplement, there was also helpful bacteria in his GI tract. This helps digest food and keeps the intestinal wall healthy. The boy used Peptamen Junior, a casein hydrolysate formula for children with impaired GI function, for some time, but then his parents took him off of it due to a casein allergy. This appeared to trigger developmental leaps and the boy showed sudden improvement in behavior therapy. He said "daddy" for the first time, began babbling and began repeating what other people said. Because of these improvements, the family was motivated to continue avoiding casein and casein hydrolysates. The family and the boy had experienced considerable frights with anaphylaxis, severe allergic reactions that could lead to death. The boy was anxious about his throat closing. At consult he was quiet, anxious/avoidant, extremely pale and had dark circles under his eyes. He did not want to enter the occupational therapy treatment room, normally a fun space for toddlers. Stools were chronically loose and the boy had 3-6 per day.

Assessment/Plan:

Anaphylaxis was a serious concern in this case, making rotating diets or trying some new foods impossible. Food intake was low for total calories, total protein, protein quality, and fats. Twenty-four ounces per day of EO28 plus any tolerable solid foods was recommended. Supplements included daily recommended intake of vitamins A and D (cod liver oil), magnesium, zinc, chromium, selenium and iron. Antifungal therapy was recommended.

Outcome:

The child was willing to drink EO28 and tolerated it well. Supplements and antifungal treatment were used also (fungal infections were treated with herbal medications, due to the increased risk of usingazole antifungals with his other medicines). At the final follow up visit eighteen months later, the child had rebounded well on height for age to 85th percentile. This implies adequate protein intake and absorption. The boy was eager to explore the occupational therapy treatment room and did so with a friend, rough-housing and bouncing on mattresses and playing appropriately. Muscle tone was lower than typical for his age, but much improved since his first consult. Stools were more formed and less frequent. Developmental and language delays were still present but also much improved. In this case, due to multiple food allergies and sensitivities, the nutritionally complete formula with free amino acid source for protein was critical to restoring the boy's nutrition status. He grew and developed well on it compared to Peptamen, which contains casein peptides.