

# Mealtime and Children on the Autism Spectrum: Beyond Picky, Fussy, and Fads

Contributed By: [Marci Wheeler, M.S.W.](#)

Eating and feeding are common topics among parents of young children. First time parents learn and gather information about how and what to feed their children, what to expect during different stages of development, and how to promote positive and healthy eating habits. Many children develop what are described as mild feeding or eating problems at some point in their development. Doctors may take a few minutes at each visit to screen for feeding and diet issues along with measuring growth status. Doctors and nurses will listen and give some guidance for common feeding and nutrition issues. Many problems of picky eating and mealtimes are resolved with a little guidance and some patience. However, parents of children on the autism spectrum often seek further guidance and support for what are frequently much more severe eating problems.

Many parents of children on the autism spectrum struggle with their child's severe eating problems with little or no professional help. In part, this is simply due to the limited number of specialists dealing with eating and feeding disorders. Furthermore, within this limited number of specialists there are few that have much understanding and experience with children who have autism spectrum disorders. A frequently suggested strategy for many children with eating and feeding disorders involves withholding food until the child is hungry enough to eat. This approach has been shown to be dangerous and not appropriate for a child on the autism spectrum. Unfortunately, professionals as well as concerned family members and friends mistakenly blame parents of children with autism spectrum disorders for their child's poor eating habits. Sometimes parents' concerns are ignored and they are told not to worry since most children go through stages of picky eating and food fads.

Though no reliable statistics are available on feeding and eating disorders of children on the autism spectrum, it does appear to be relatively common. Families of these children may end up struggling on their own with little understanding from family, friends and the professional community. One British mom, out of loneliness and frustration, attempted a survey that resulted in a sample of 89 questionnaires being filled out and returned. Brenda Legge's (2002), *Can't Eat, Won't Eat: Dietary Difficulties and Autistic Spectrum Disorders*, in which she summarizes feeding and eating problems experienced by families, can undoubtedly serve to assure families that they are not alone. Though each child is unique, information gathered from her survey shows the need for further research on this issue and serves to educate families about some common eating issues.

Medical, behavioral, and environmental factors, including sensory difficulties, must be considered when feeding and eating problems occur. Within the scope of this article, medical and behavioral factors will be addressed briefly. Medical issues and frequently, behavioral issues, need to be assessed and addressed by working with the appropriate professionals. The environmental and sensory related issues will be discussed and outlined in more depth. It is the environmental and sensory related problems that families can often adjust on their own once they better understand their child's needs.

Medical conditions can affect a child's eating habits and eating habits impact health. It is important to assess and address medically related feeding problems first so that the child's health needs can be recognized and managed. After medical problems have been examined, and plans are in place to address these problems, then the behavioral problems, if any remain, are important to address and treat. Occasionally behavioral issues are so severe that medical intervention is needed for these issues also. Environmental issues including sensory difficulties can be considered after medical and behavioral issues have been treated.

## Medical Assessments for Feeding and Eating Skills

Medical assessments can include evaluation of oral motor function including swallowing studies, assessments of food sensitivities and allergies, medications and their effect on eating, and a profile of the child's diet and resulting nutritional issues.

An eating history should be taken. The eating history should include gathering the following information:

- Details of extensive choking, coughing or gagging when eating;
- Loss of oxygen (turning blue/purple) while eating;
- Pattern of liquids or foods that emerge through the child's nostrils when eating; and
- Reoccurring respiratory difficulties and/or pneumonia.

An occupational therapist, speech and language pathologist, and nutritionist or dietician along with a doctor and a nurse are all involved when a team approach is used for a feeding assessment. Frequently a social worker or child psychologist is also part of a feeding team.

In recent years, an additional aspect of medical assessments for children with autism spectrum disorders related to eating and feeding issues has been suggested. Since the late 1990s, abnormal gastrointestinal functioning of many individuals with autism spectrum disorders has gained increasing recognition and concern. Research by Doctor Andrew Wakefield, and other research by pediatric gastroenterologist Tim Buie and gastroenterologist Arthur Krigsman, suggest that at least half of all children with autism spectrum disorders have clinically significant gastrointestinal symptoms. These researchers have conducted intestinal biopsies and other assessments and have found unique forms of inflammatory bowel disease including enterocolitis, esophagitis, and gastritis in children with autism spectrum disorders.

Treatments of these digestive system abnormalities have led to varying degrees of improvements in the core symptoms of autism spectrum disorders, including behavior, communication and social skills. The main treatments for this abnormal inflammatory bowel disease include diet, treatment of gut yeast, and supplemental enzymes. More information can be found about biomedical treatments related to gastrointestinal problems and autism spectrum disorders in books by Jaquelyn McCandless, M.D., William Shaw, Ph.D. and Karen Serrusi. These books are listed at the end of this article. The Autism Research Institute established the Defeat Autism Now! (DAN!) organization in 1995. DAN! sponsors conferences, develops and disseminates written materials, and keeps a database of practitioners who are doing research and treating children with this new biomedical model. You can access this information on their website at <http://www.autism.com/ari/>.

Different diets seem to help some people with autism spectrum disorders. A gluten-free, casein-free diet seems to be where many families start when exploring a gastrointestinal connection between their child's behavior and their diet. Families often anecdotally suggest they find their child's self-imposed restricted food choices do expand significantly when they start a gluten-free, casein-free diet. The Specific Carbohydrate Diet (Gottschall, 2002) is also gaining a lot of interest among families of children with autism spectrum disorders. It is best to read the latest research and information, and find a knowledgeable medical professional to work with if you are considering a particular diet, gut healing treatment and/or supplements for your child. This approach certainly does not work for everyone, is very individualized and is a substantial commitment to most families if or when they begin.

When a child is continually refusing food or having other feeding or eating difficulties, it is important to evaluate any possible medical problems and determine factors to be addressed medically that will maximize feeding and eating success. Unfortunately, some children do not seem to have much appetite at all. They may not have the ability to feel or interpret the feeling of hunger. This inability to feel or interpret hunger is confusing and usually

means more effort on the part of families to feed their child because s/he will have little or no interest on their own. Food allergies and food intolerance should also be considered as part of medical testing. The lack of ability to detect hunger, food allergies, and/or food intolerance can also impact eating issues and ultimately the child's health.

## Behavioral Problems that Effect Feeding and Eating

Eating disorders are complex and continue to be studied among various populations. Eating disorders such as failure to thrive, rumination, pica, obesity and anorexia nervosa can affect children with autism spectrum disorders. Children experiencing these problems are at risk for serious health and growth problems that can lead to life threatening consequences. It is frequently mentioned in the literature (Kedesdy & Budd, 1998; Macht, 1990; Woolston, 1991) that individuals with disabilities may be at a greater risk for these types of behavioral eating disorders.

Pica, the ingesting of non-nutritious substances, is a behavior that can start at any point in life under various circumstances. If a child is persistently eating non-edible items such as paper, dirt, or craft items and/or chewing on plaster or wood, an evaluation should be done to try and determine the cause. Obviously the child should be closely supervised and kept away from substances related to this pica behavior. There are multiple causes and treatments for pica. A knowledgeable professional can assess and address pica. Nutritional deficiencies, sensory stimulation, lack of ability to discriminate non edible items, and relief of anxiety are all possible factors that can lead to pica. If the pica is not seriously health or life threatening, sometimes substituting edible and/or sensory stimulating alternatives can take care of the problem.

Rumination is the persistent regurgitation, re-chewing, re-swallowing, or occasionally vomiting of previously eaten foods and is a second behavioral problem of eating that can have serious health consequences. The causes of rumination are not clear but are thought to begin due to gastro-intestinal disorders and continue due to the self-stimulatory rewards the individual experiences. Rumination is a relatively rare disorder; the best course of action is an appropriate medical assessment and treatment. Behavioral interventions may be appropriately designed and implemented once medical issues have been thoroughly addressed. Behavioral issues, when severe, will also need to be assessed and treated medically.

## Environmental Problems that Affect Feeding and Eating

Throughout the limited feeding and eating disorders literature (Morris & Klein, 1987; Kedesdy & Budd, 1998; Macht, 1990), environmental factors primarily focus on sensory processing variables. Children with extreme food selectivity issues are frequently dealing with many environmental factors related to sensory modulation and regulation. Selective eating is defined as eating very small amounts of food and/or restricting foods eaten to an extremely narrow selection of sometimes only one or two items. Selective eating can have significant developmental and health consequences. Extreme selective eating problems are often seen paired with strong negative reactions to the introduction of new foods. Mild selective eating is common in all toddlers and young children according to a variety of studies. It cannot be emphasized enough that the issue of concern for a significant number of children on the autism spectrum is extreme food selectivity.

Extreme food selectivity, when related to environmental and sensory issues, can be addressed successfully in many cases. The place to start is to analyze eating habits and then sensory variables. Gathering information about what the child eats successfully, and about how, when and where the child eats best can provide clues for broadening the child's diet. The following questions should be answered: what foods, with whom, where, when and how does the child eat any foods even if it is just a few foods. Frequently, there is a pattern to what foods the child eats or where the child eats successfully.

Parents often discover their child's interest in or avoidance of, particular foods is related to a common sensory experience. A description of common sensory processes related to eating and the various sensory factors are discussed below. Do you know what sensory inputs are motivating to your child? Is your child avoiding certain sensory inputs?

Some children with autism spectrum disorders will eat mostly foods that fit into only one of these four categories; sweet, sour, bitter or salty. It is common, for example, that a child will choose to eat mostly or only foods which are salty and not be interested in sweet foods. Food that is "naturally" salty such as chips, bacon and crackers may make up a majority of a child's diet. This pattern may alarm parents and motivate them to seek information and help.

There are some children who seem to figure out that all food tastes better to them with catsup or occasionally some other condiment. The family and professionals may decide that these toppings are fine as long as it is helping the child get more of the nutrition they need from the foods which they would refuse to eat without their preferred "topping."

The "feel" or touch of the food is commonly a sensory factor for individuals with an autism spectrum disorder. The temperature or texture of foods needs to be just "right." It is common for children to insist on all foods being at room temperature. This may mean that cold foods such as ice cream or popsicles are not tolerated and that foods that are cooked need to be cooled to room temperature before the child will eat them.

It is also common for children with autism spectrum disorders to have a strong preference for one particular texture of foods such as crunchy or smooth. Mashed potatoes must be the same consistency each time for example. When introducing new foods, it is important to consider introducing foods that are of the similar texture or which can be modified to be of similar texture. Some children have a harder time, then typical children, transitioning from foods they can eat with their fingers to foods that are eaten with utensils. The transition from the bottle can also be more problematic for children on the autism spectrum.

Some children with an autism spectrum disorder are much more affected by the smell of food. The smell of foods that are not familiar and comfortable may affect their ability to eat. This may affect their ability to go places outside of their home to eat. Some extremely sensitive individuals may not be able to eat at the same table or in the same room where others are eating a food that has an uncomfortable and/or unfamiliar smell. Be aware that smell could be affecting your child's eating issues.

The way foods "look" is another issue to be aware of when eating and feeding are problems. It is common for parents to share that their child only eats foods of one color such as only white or orange foods. Many children on the autism spectrum will only eat something if it is presented each time in the same type of plate or container. Some extremely selective kids will want "perfect" uniformity of their food and will refuse to eat if they detect even the slightest change.

## Strategies for Addressing Eating and Feeding Problems

When developing a plan for expanding the number and variety of foods a child will eat, it is important to be calm and not controlling. In fact the most successful experiences are when the child is given some control or at least they perceive that they do have some control. Struggles over eating most often make matters worse. Gradual exposure to new foods can be very important. Frequently, in despair, mothers will offer a different array of several new foods each day hoping that by chance the child might try something. The more choices the more chance of success, sounds like it makes sense, but not for a child on the autism spectrum.

Gradually introducing a new food will help the child to become desensitized to the smell, look and possibly feel of an unfamiliar food. If a new food is chosen that has highly desirable sensory qualities to the child, you will have a better chance at success. Start with a food that has the "best" sensory fit. Offer the food on a daily basis by putting it where the child will be able to desensitize to it. Think of how your child might best accept a new item in his/her space. Frequently a small separate bowl or plate in close proximity to the child's seat will work. Sometimes a child can tolerate the new item on his or her plate as long as they understand that the only expectation is that it will just stay on their plate. Repeated exposure of the identical food item should be offered once or twice a day, at meals, with no expectations attached. Sometimes this technique paired with others in the family, especially a sibling, modeling the enjoyment of eating this new item, can make it easier for the child to try tasting it. You may try the same food item for two or three weeks. For children who respond to Social Stories (Gray, 2000; Gray & White 2003), information can be offered in this format, at times other than mealtime. In the Social Story, focus on the wonderful benefits of trying this new food. Sometimes, in the Social Story, describing a favorite character like Barney or Spiderman eating this particular food gets them interested enough to taste it.

If desensitization, modeling and a social story have not resulted in the new food being tried, the strategy of offering alternating small bites of a highly desirable food with a small bite of the new food is another option. As always, it is important that this technique not be made into a battle. The idea is to make trying a new food as pleasant and successful as possible. This is a common strategy that is used for all children. The information can be made visual (by putting the different bites in view on the plate) along with the instructions "First *favorite food*, then *new/undesired food*, and then *favorite food*." An example might be "First macaroni, then peas, and then macaroni." Both of these approaches for introducing new foods are positive and non-threatening to the child. The child can feel like s/he has some control.

Children do not want to be tricked. Tricks such as hiding "extra" vegetables in spaghetti sauce and or supplements in a child's favorite drink do sometimes work but can also backfire. Sometimes, after detecting "additions" to familiar favorites, the child learns to be suspicious of all foods and will limit his/her diet even further. This strategy probably works best when the sensory characteristic the child is focusing on is the "look" of the food. If a child is more sensitive to the smell, taste or texture of a food, it may be harder to make "additions" because they are usually easier for the child to detect. Be cautious when using this strategy.

The auditory sense is generally not directly related to eating and feeding issues. Indirectly sounds can contribute to the comfort of the actual environment where eating and feeding take place. It is very common for individuals on the autism spectrum to get overwhelmed in noisy and crowded environments such as a school cafeteria or McDonalds on a Saturday afternoon. It is important to accommodate individuals' needs so that the environment itself is not preventing successful eating because of sensory overload. Some children take longer switching from a bottle to a cup or learning to use utensils. Part of the issue is that change is hard for these children in general. The sensory issues can also be a partial reason for this difficulty. A desensitization plan for using a cup and/or utensils can be developed. If the problem is severe, an occupational therapist with sensory integration training may be helpful in suggesting desensitization techniques. Sometimes adaptations are possible and appropriate such as allowing the use of plastic utensils instead of metal.

In addition to the sensory properties of foods and the sensory stimulus in the environment affecting the child's ability to eat in a particular environment, a third common issue is the ability to sit at a table and eat a meal with others. There are a number of reasons why this may be difficult. Eating at a table with others is a social activity. Eating may not be a very motivating or rewarding activity in itself. Pair that with the social issues involved in eating with others and you may begin to better understand the situation from your child's perspective. Additionally, many of our children are active and have a hard time staying still in one place no matter what the

activity. There are several possibilities to address when looking at the issue of sitting at the table with others to eat.

Determining the reason your child is not able to sit at the table will help in deciding what to do to address your child's needs. Some children need to organize their bodies with a little physical activity before they are asked to sit at a table. Sometimes a timer needs to be set to show more concretely that sitting is expected at mealtime, at least for a few minutes until the timer rings. The length of time a child is expected to sit may be gradually lengthened so success is built up slowly. Some children can sit and eat quickly at the table but will not be able to sit and wait for others before being served and/or after they have finished their food. This inability to wait can sometimes be addressed with special waiting toys or activities. Sometimes items to focus on while waiting are helpful. Even some older children and adults on the autism spectrum have a need to develop waiting strategies to use at mealtime while eating with others. In this situation, bringing something to read or a pocket sized game to focus on while waiting, is a positive coping strategy for older children and adults, too.

Eating and feeding problems can sometimes dominate family life. It is easy to get overwhelmed when eating problems are severe and are so closely tied to your child's health and development. The fact that mealtime occurs at least three times a day, and families and children are not always able to eat at home, adds to the stress. Get help for any biomedical and behavioral concerns. After those areas are addressed, families' can often tackle the environmental factors by calmly working to desensitize the child to new foods with structure and a non-controlling plan for trying a new food. The expectation to sit and eat at the table can be structured in small steps and paced so the child is successful. Patience with this process is also a key to success. Network with other families to share successes and failures, and to gather new tips or resources that can make a difference. Also when you reach out to others you will be reminded that you are not the only one coping with these challenges!

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