

Question from a Parent regarding food sensitivity in the Down syndrome population posed to and responded by:

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Dear Carolyn,

Sara R. Johnson told me I should contact you concerning the effects of sugar, white flour, caffeine, food coloring, etc... I've had professionals tell me that children with special needs are sensitive to all kinds of foods and I'm trying to find how I can best meet our child with DS's nutritional needs.

Thanks for your help and time, Linda

Linda,

Thank you for your inquiry.

It is true that certain children are exquisitely sensitive to certain foods. Often, scientific studies fail to confirm this because statistical methods demand that all subjects be lumped together during data analysis. However, when data on individuals is considered, it is found that a small percentage of subjects show a clear and dramatic reaction.

In DS, in particular, all forms of wheat (not just white flour) and other gluten containing substances should be a concern. Frequently, DS children and adults can display gastrointestinal, immune and neurological symptoms as a result of exposure to gluten and its resultant toxins. Gluten sensitivity can appear at any age, and can be subtle or obvious. The proven propensity for DNA damage in DS is certainly a factor in gluten sensitivity's increased incidence among this particular population. Gluten sensitivity can be present even when antigliadin testing is negative. The only gold-standard of diagnosis is a tissue biopsy. Many parents opt just to try the gluten-free diet and watch for improvement. If you choose this route, you must be absolutely faithful to the diet, as even small exposures to gluten can do further damage or prevent the intestines from healing. Most sensitive people will respond quickly to the removal of gluten from the diet, but some patients take months to respond, so plan to stick with it for a year before concluding that it is of no value to your child. Here is a link to the gluten-free diet information provided by GIG, the Gluten Intolerance Group <http://www.gluten.net/diet.asp>.

Sugar is also a concern, as it can compromise the immune system, contribute to the gum disease seen in a large percentage of DS children and adults, and prime the body for obesity and cardiovascular problems later in life. All of this is in addition to the effects of sugar seen in sensitive individuals in general. When sugar is used, it should always be part of a food, snack or meal that also includes complex carbohydrates, protein and hopefully, a reasonable amount of fat. This applies even to "healthy" sugar sources such as fresh fruit. Sugar primes the body to digest an entire meal and when eaten alone, it will cause a plunge in blood-sugar that can lead to a multitude of behavioral, neurological and physiological problems in sensitive individuals.

Caffeine is well known to cause both positive and negative neurological symptoms in a large number of people and is of special concern in children. I feel strongly that high-caffeine foods and beverages have no place in the diet of a child and should be taken only in moderation even by adults.

Food additives, though sometimes harder to pin-down, can certainly have a dramatic effect in certain sensitive individuals.

Allergies and sensitivities to common foods can also be a problem. Milk, wheat, eggs, citrus, nuts, berries, and pork are common culprits, though even foods considered to be hypoallergenic can affect certain individuals. Early introduction of solids, lack of adequate fiber in the diet, repeated antibiotic use without follow-up recolonization with friendly bacteria (effective recolonization can require several months of supplementation), gluten sensitivity and multiple allergies all tend to increase the likelihood of development of new food allergies.

I am particularly concerned about the lack of fiber in the diets of many DS children due to delayed introduction of solids and long-term feeding issues. The health of the intestines affects the immune system and the incidence of allergies. Soluble fiber is the main source of nourishment to the cells lining the intestines and lack of fiber compromises the intestines' ability to function as the body's first line of allergy defense.

And, of course, there is special concern with adequate intake of particular nutrients such as antioxidants and the B-vitamin triad Folic Acid, B6 and B12 in DS to hopefully limit oxidative stress and inflammatory response. I also believe that Vitamin D status is especially important in protecting the immune system of DS individuals.

In evaluating food sensitivities and special nutrient needs, each child must be looked at individually. Some cases are simple and straightforward, but the process is often complicated and may involve a great deal of trial and error, professional feedback and parental intuition. Of course, there is no guarantee at the outset that any particular child will prove to respond positively to a particular elimination or supplementation program, but a carefully designed program will at least cause no harm and has the potential to bring about mild, moderate or dramatic changes. A carefully kept food diary, coupled with a well-planned elimination diet plan is the first step in pinning down food sensitivities. The health history of other family members can also give clues to special needs.

I don't know how deeply you wish to address these issues. If you feel you would be interested in exploring dietary changes that would "make-sense" for your child's particular situation, I would be happy to work with you. It would be helpful if you would email or fax me an overview of your child's medical history, your concerns and your basis for them, etc.; so that I can see what you have already done and what potential changes might help. Once I have this information, I may be able to point you to specific informational materials that you can pursue on your own, or we can arrange for a telephone consultation if you wish.

Thank you for contacting me. I look forward to hearing further from you.

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