

A compilation of advice for using the Low Oxalate Diet for Autism

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<http://www.mystillpoint.com/resourcecenter/>

(For more information about incorporating the low oxalate diet see Susan Owens online support group at Trying_Low_Oxalates at Yahoogroups.com or http://groups.yahoo.com/search?query=trying_low_oxalates)

Theory: Why may someone with autism need a low oxalate diet?

Oxalate is a highly reactive molecule that is abundant in many plant foods, but in human cells, when it is present in high amounts, it can lead to oxidative damage, depletion of glutathione, the igniting of the immune system's inflammatory cascade, and the formation of crystals which seem to be associated with pain and prolonged injury. Ordinarily, not much oxalate is absorbed from the diet, but the level of absorption has to do with the condition of the gut. There is a lot of medical literature showing that when the gut is inflamed, when there is poor fat digestion (steatorrhea), when there is a leaky gut, or when there is prolonged diarrhea or constipation, excess oxalate from foods that are eaten can be absorbed from the GI tract and become a risk to other cells in the body. Since these gastrointestinal conditions are found frequently in autism, it seemed reasonable to see if lowering the dietary supply of oxalates could be beneficial.

We quickly learned that people who had been eating a very high oxalate diet before getting on the low oxalate diet may experience a temporary worsening of autistic symptoms that we think represents oxalates leaving cells where they were sequestered before and having biological effects. This process of oxalate release has been described in genetic hyperoxalurias where the source of the oxalate was metabolic rather than from the diet, but the process is likely to be the same. On the far side of these periods that we've started to call "dumping", improvements were noted to occur in the genetic hyperoxalurias. In our project with children with autism, we also began to see improvements that involved symptoms associated with autism. Those changes included the resolution of bowel problems that had not responded to previous therapy, and introduced the concept that the bowel itself might have injury prolonged by exposure to oxalate. Our project also was pleased to find improvements occurring in gross and fine motor skills, in speech and in growth, in stimming, and in many other areas commonly seen in autism.

Our Autism Oxalate Project has been focused on learning from the medical literature and from parent observations which dietary supplements and other strategies can minimize the down side of these periods of increased symptoms. This document will summarize the best advice we have accumulated so far regarding what helps in the management of this diet in children on the autism spectrum.

As you plan to begin the diet:

Before starting the diet, it is a very good idea to start looking at lists of low oxalate foods and compare that to the diet that the child has been eating. Use that to assess whether the child has been eating a normal diet or a very high oxalate diet.

The VP Foundation has printed a book called **The Low Oxalate Cookbook, Version 2** which can be bought from the web at the following address:

<http://www.vulvarpainfoundation.org/vpfcookbook.htm>

This book is extremely helpful, as its food charts are more complete than other lists you will find on the internet or in books. This cookbook lists oxalates in mg per serving and per weight. It may take weeks to get this shipped to you, so ordering this book is something you might want to do early. Wellness Pharmacy also may have copies and may be able to ship faster and charge it to a credit card: <http://www.wellnesshealth.com>. They also sell the probiotic VSL#3.

If the child has been eating a very high oxalate diet, especially for a long time (months to years), his symptoms at the beginning of the diet may be more severe than in someone who was eating an ordinary diet. It may be best in such a person to cut out the extremely high oxalate foods first for at least a week before starting to eliminate the medium oxalate foods. This way you can work your way gradually into a completely low oxalate diet. Most parents whose children have made excellent progress on this diet have found that it is necessary to restrict the diet to only low oxalate foods for a period of time (weeks to months) in order to see the true benefits from this diet.

Be sure as you plan what you will buy and serve for your child that your food choices are going to be providing adequate nutrition. Many grains are high oxalate, so that when they are removed from the diet, it may be more difficult to keep the calorie count high enough.

The following is a very general guideline for calories in children, but please get specific information from your doctor.

Ages 2-6: 1,600 calories per day
Ages 6-12: 2,200 calories per day
Teen girls: 2,200 calories per day
Teen boys: 2,800 calories per day

The amount of oxalates for an adult on a low oxalate diet should be between 40-60 mg a day on a 2000 calorie diet. Please keep the proportions of oxalate to calories similar to this, i.e. 33-50 calories for each milligram of oxalate.

Parents have noticed that it seems very important with the low oxalate diet to supply the gut with flora that can degrade oxalates that begin to be released, especially because one of the routes oxalates will take as they leave the body is through the intestine. If there are oxalate-eating microbes present in the colon then this process will be easier. We have found the best probiotic currently on the market has been VSL#3 which was developed for ulcerative colitis and pouchitis and can be purchased on the internet (**New Beginnings – www.nbnus.com - also carries VSL#3 – Dr. Woeller**). Since it may take some time to get your order delivered, ordering this as soon as possible will make it easier to start the diet. Some parents have made yogurts from coconut or goat milk adding VSL#3 to the culture. Soon, we hope the prescription probiotic for the anaerobe oxalobacter formigenes will be available which is now in development and should work even better.

It also is important before beginning the diet to have on hand calcium citrate, magnesium citrate, and the antioxidants Vitamin A & E. Vitamin C is not used as an antioxidant on this diet because a large proportion of vitamin C appears to be converted into oxalate over a period of about one to two weeks or longer. The Vulvar Pain Foundation, with much experience in tracking oxalates in patients, recommends keeping Vitamin C intake at or below 150 mg/day.

Many parents find it useful to have ready some pH testing strips so they can see if the diet is changing urinary or salivary pH. Some have noticed big swings in pH during the regressive periods, and there are ways to address this by choosing foods that help move the pH up or down. These websites might help:

<http://www.ctds.info/acidic-foods.html>
<http://www.care2.com/channels/solutions/food/1371>
<http://www.liferesearchuniversal.com/acid.html>
<http://altmedicine.about.com/od/popularhealthdiets/a/alkalinediet.htm>

Occasionally, the regressive periods can be so severe that it worries the educators working with your child. For this reason, especially if you have a child who has been high oxalate for a long time, it may be a good idea to begin the diet a few days before a school break (during what we call the "honeymoon" or the first few days of improvement.

This way the regression, if there is one, will hit during the time off. Also, be sure your child's doctor will support you with a letter to explain that negative changes are temporary and the child is likely to be much better after this period is over.

Supplements and other things that help during the diet:

Arginine: Important for replenishing nitrous oxide that helps to reduce oxidative damage from oxalates.

Taurine: important for making bile acid taurocholate which limits absorption of oxalate; take if stool turns yellow.

Vitamin A: Important for helping to close the leaky gut and important as antioxidant.

Vitamin E: Important as an antioxidant.

Lipoic Acid (ALA): Works for some, not for others; important antioxidant and can prevent some endogenous production of oxalate.

NAC (N-acetyl cysteine): Important for restoring glutathione that gets depleted by oxalate; sometimes there are negative reactions.

Lipoceutical glutathione: Helps restore glutathione; helps reduce metabolism of glycolate to oxalate; helps behavior on diet (meltdowns) for some children. This is available at Wellness Pharmacy: <http://www.wellnesshealth.com>. *New Beginnings as well – Dr. Woeller*

Lemon juice: Helps with digestion when given before eating and may help balance pH issues when acidity is a problem

Antihistamine: Oxalate may cause histamine release so this counters that. Do not use an antihistamine formula that includes a decongestant.

Thiamine and magnesium: Important for keeping meat from being metabolized towards oxalate.

Pantothenic acid or CoEnzyme A: Important to keep from making oxalate by glycolate cycle in microbes and us.

Vitamin B6: Important for preventing metabolism of food to oxalate.

Citrate (calcium or magnesium): May prevent crystalization of oxalate and may help break down crystals already formed.

Calcium: Important to take before meals to bind to oxalate and prevent its absorption: timing critical to this effect!

Magnesium: Can be depleted by oxalate and may help with constipation and may bind oxalate.

Lipase or ox bile: May help if steatorrhea (fat in stool) is leading to excess absorption of oxalate.

Epsom salts baths: Can be calming; occasionally may cause rashes but this may not be a bad thing, as it may be helping get rid of oxalate in the skin.

Bicarbonate: sodium bicarbonate or Alka Seltzer Gold can help with behaviors.

Zinc: May be depleted by oxalate; response and need for zinc seems to change rapidly on diet; play with dose.

You may want to cut back on:

Vitamin C: It can be metabolized to oxalate. The effect may be delayed by as much as two weeks.

Fish oils: If there is poor fat digestion, this may cause more absorption of oxalate. Try it with and without to see which is better. The vitamin D in some fish oils may be a problem for some children.

Vitamin D: Vitamin D may cause enhanced absorption of unbound calcium in the gut, and this can lead to increased free oxalate being absorbed from food. For this reason, calcium taken at the beginning of meals for the purpose of binding oxalate should not include added vitamin D. Calcium taken away from meals may contain Vitamin D.

Iron: Some have seen improvements in iron status on diet; may be needed at the beginning.

Nystatin: This may possibly keep the gut leaky through effects on the membrane that lies at the tight junction. Try eliminating it and see if that works better.

PEG compounds like glycolax or Miralax: These may be converted with the help of microbes into oxalate. Especially discontinue if you see symptoms.

Other supplements or medicines: Need for supplements tend to change on this diet. Many find that they are able to eliminate parts of their supplement program gradually, including anti-yeast strategies. Others find their gut heals so well that they do not any longer require gastrointestinal medications. Work this out with the help of your child's doctor.

Do not be surprised if:

1. Your child has a temporary worsening or onset of urinary issues like penis pain, redness, urinary frequency or urinary urgency.
2. Strange rashes appear that you have not seen before - check website photos for comparisons with other listmates using diet This can include Livedo reticularis, which is an inflammation of blood vessels that makes them show up vividly in the skin, looking a little like a roadmap.
3. Oxalate crystals can cause gum problems, and in rare cases can lead to re-absorption of the roots of teeth, which starts to make the teeth become loose. If symptoms of this type begin, you may need more antioxidant protection.
4. Behavioral regressions, speech regressions, etc. These may be caused by oxalates circulating that were in cells. This will pass, but it can be a really difficult time. Read listmate reports for encouragement through this period but supplements may help and probiotics help as well. Do work closely with your doctor until this time passes if it gets severe.
5. You see an onset of diarrhea including sometimes very sandy stools and stools with black specs. (This may be oxalate, but we don't yet have stool testing to confirm that.)
6. Rarely, in some children, infections of streptococcus may reappear, along with symptoms known as PANDAS, and we are not certain why this happens. It may be that in past infections, oxalate crystals formed around the bacteria and the bacteria were later liberated when the crystals broke down under the influence of the diet. This will need to be studied, but a similar mechanism has been noted when oxalate crystals have formed around other infectious agents like E. coli.
7. Negatives are generally positives in that these symptoms shouldn't show up in someone unless they have had an oxalate problem, and these bad periods seem to be followed by resolution of issues that were problems before.
8. Your child starts being willing to eat foods he avoided before and stops craving high oxalate foods.
9. Your child gets ravenous during "dumping" stages, or ends up satisfied with less food after being on the diet for some time.
10. Your child who has not grown for a long time suddenly has a growth spurt.

11. Your child's OAT or a 24 hour oxalate test measured oxalate within the normal range or not very high, and your child still ends up being a very positive responder to the diet. Differences in the sulfur chemistry in autism may make it where oxalate has trouble collecting in kidney tubule cells so that it can leave through secretion into the urine. This issue is being studied.

Useful substitutions:

Most flour substitutes for gluten are high oxalate. Try coconut flour or pumpkin seed flours. These do not work for everyone. Many have had success with rice flour. If SCD before, try introducing just a little rice flour in some other food and gradually work up to cooking with it and using regular rice. Many do stay SCD while LOD, and there is a lot of help for doing this from other parents, but it does narrow the food choices and makes getting enough calories a challenge.

Most milk substitutes are high oxalate, such as brown rice milk, almond milk, potato milk. Some have had success with either goat milk or coconut milk.

Don't be afraid that the low oxalate fruit will kick off candida. This doesn't seem to happen in most children. In fact, many children find that their tendencies to have dysbiosis and yeast infections will go away on this diet.

Disclaimer: We are assuming that those attempting this diet are under the care of a physician, and we also advise you to talk to your physician about any problems you encounter that could benefit from his or her professional advice. The dietary advice listed here is not medical advice, but many things we do in life have medical implications. Keep your doctor in the loop for they are there to provide oversight.