

FREQUENTLY ASKED QUESTIONS ABOUT...

DIET for ATAXIA

SOME GENERAL GUIDELINES & CAUTIONS

These diet suggestions are for discussion purposes with your physician only. These diet ideas have not been proven to work with all forms of ataxia, nor have they been tested with a sufficient sample of ataxia patients to recommend their applicability for any specific patient. More research on diet's effect on ataxia is needed. These dietary ideas should not be tried without first consulting with your treating physician as to their potential usefulness in your particular situation.

The overall rationale of any diet regime for ataxia is to: (a) reduce bothersome symptoms; (b) reduce reliance on poorly tolerated or contraindicated pharmacotherapies; and (c) enhance the ataxia patient's perception of personal control and sense of responsibility for the management of his/her neurological condition.

Work with your physician(s). Ask the physician to include copies of their clinic notes to you, as well as the other specialists you see who need to know about that visit. Make a notebook that includes physician notes, a schedule of the pharmacological agents you are taking (drug, dosage, frequency, when trial started, when trial ended, any side effects), and your "lab notes" related to each trial and its effects on neurological condition during the study time period. Talk to the doctor about your expectation as to hearing back from them, either in writing, by phone or via email within some set timeframe.

Reserve your visits to the doctor for those periodic visits that require physical interaction and physical measurements best done in the doctor's office or if you have a true emergency. When you visit the doctor, bring your lab notebook along just in case he/she is missing some key data that has not been forwarded from one of your other specialists. Neurological problems are typically 'systems problems' that will require all the physicians who you are seeing, as well as you, being on the "same page". Having good data is key to making good decisions going forward.

Diet without exercise is typically not as beneficial. With the advice of your physician design an exercise program that you will faithfully do for at least 30 minutes each day, at least 4 days each week, year-in-year-out.

WHAT ARE THE PURPOSES OF AN ATAXIA DIET?

- Sound nutrition to support healthy body weight and normal bodily functions. It is important to achieve an appropriate body weight for improved movement ability and lower stress on joints.
- Increased energy.
- High fiber which may add regularity to bowel movements.
- Improved mood and spirit.

A SIMPLE CARBOHYDRATES-RESTRICTED DIET MAY BE HELPFUL

Ataxia patients may sometimes benefit by avoiding all simple carbohydrates and reduce foods sweetened with high fructose corn syrup: cookies, cakes, candies, pastries, white flour, and fruit juice. Eat complex carbohydrates: unsweetened fruits, starchy vegetables, legumes, rice, and pasta. Avoid processed meats: cold cuts, hot dogs, bacon, and foods with additives and preservatives. Drink plenty of water; 6 to 8-8oz. glasses/day. Avoid sugar drinks and fruit juices.

ARE THERE ANY OTHER FOODS I SHOULD AVOID?

The foods in the table below, when avoided, sometimes help ataxia patients by reducing dizziness and improving a sense of balance:

TABLE 1: FOODS THAT IF AVOIDED MAY REDUCE DIZZINESS AND IMPROVE A SENSE OF BALANCE IN SOME ATAXIA PATIENTS

Aspartame	No foods containing NutraSweet are allowed.
Breads, fresh baked	Avoid freshly baked breads less than 1 day old.
Chocolate	No dark or milk chocolate or foods containing chocolate are allowed. White chocolate is OK.
Citrus-Containing Foods	Avoid citrus fruits and their juices – as well as bananas or foods with bananas as ingredients..
Monosodium Glutamate (MSG)	No foods with MSG are allowed. This includes all foods with hydrolyzed protein as an ingredient.
Nitrate/Nitrite-Containing Foods	No bacon, hot dogs, sausage, ham, smoked fish, etc. with nitrates or nitrites are allowed.
Onions, raw	Avoid raw onions. Cooked onions may be tolerated.
Sulfite-Containing Foods	Avoid raisins, dried fruits, dates, figs, etc. preserved w/ sulfites.
Tyramine-Containing Foods	Most cheeses (cottage cheese, ricotta, cream cheese, and American cheeses are OK), pizza, yogurt, sour cream, buttermilk; beef liver, chicken liver; all nuts, including peanut butter (seeds are OK); soy sauce and foods containing hydrolyzed soy protein; beans such as lentils, lima and navy beans.

WHAT VITAMINS SHOULD I TAKE?

For ataxia patients, taking a daily multivitamin is important to help with fatigue and general health. But, oftentimes, a multivitamin needs to be supplemented to provide MDRs (minimum daily requirements) of some specific micronutrients. Below is a list of micronutrients recommended for adults that sometimes require supplementation beyond a good daily multivitamin that ataxia patients may wish to consider taking:

TABLE 2: MICRONUTRIENTS RECOMMENDED FOR ADULTS

MICRO NUTRIENT	DOSAGE	CONSIDERATIONS
Vitamin B-12	100-400 mcg/day	Vitamin B ₁₂ malabsorption and vitamin B ₁₂ deficiency are more common in older adults.
Vitamin C	500-1,000 mg/day	Some people find sodium ascorbate and calcium ascorbate less irritating to the gastrointestinal tract than ascorbic acid.
Vitamin D-3	2,000 IU/day (50 mcg)	Vitamin D is required for optimal calcium absorption. Obesity tends to reduce bioavailability of vitamin D. Aging also tends to reduce the capacity to synthesize vitamin D. Staying indoors or the regular use of sunscreen blocks vitamin D synthesis.
Vitamin E	200 IU/d	Total sources should not exceed 400 IU/d

TABLE 2: MICRONUTRIENTS RECOMMENDED FOR ADULTS continued from page 2

Vitamin K ¹	Women: 90mcg/day; Men: 120 mcg/day	Adequate intake (AI) of vitamin K is essential in maintaining bone health.
Calcium	1,200 mg/day	Adequate intake (AI) from all sources for both Males/Females over 50. To maximize absorption, take no more than 500 mg of elemental calcium at one time. Most calcium supplements should be taken with meals, although calcium citrate and calcium citrate malate can be taken anytime. 400 IU/d of D-3 will help insure calcium absorption.
Coenzyme Q-10	200-300 mg/day	Coenzyme Q ₁₀ is fat-soluble and is best absorbed with fats in a meal. Doses higher than 100 mg/d are generally divided into two or three doses throughout the day. Higher doses of 800-1,400 mg/day of CoQ-10 have been shown in some studies to improve Parkinson's symptoms. Higher doses should only be taken on advice of your physician. Women who are pregnant or breast feeding should not take take CoQ-10.
Magnesium (Mg)	100 mg/day	The metabolism of carbohydrates and fats to produce energy in the body requires numerous magnesium-dependent chemical reactions. Mg may also be helpful for muscle cramps. Mg is best absorbed in aspartate or glutamate amino acid chelated form or alternatively in glutamate or lactate salts form. Mg oxide is less well absorbed.
Omega-3 ^{11,6,9}	2,000 mg/day	Omega 3 (ALA, EPA, and DHA), 6 (GLA, linoleic acid), 9 Fatty Acids. These fatty acids require adequate Vit.-E.
Glucosamine sulfate only. Not glucosamine HCl or with Chondroitin sulfate. Take only after discussing with your physician	1,500 mg/day for relief or arthritis pain only in some patients	Three months of treatment is a sufficient period for the evaluation of efficacy; if there is no clinically significant decrease in osteoarthritic pain by this time, the supplements should be discontinued. There is no evidence that glucosamine sulfate prevents osteoarthritis in healthy persons or in persons with knee pain but normal radiographs. Avoid if allergic to shellfish!
Flavonoids	eat fresh vegetables and fruits daily	Flavonoids may provide some neuroprotective benefits by helping to reduce inflammation in the body. Resveratrol in red wine also helps with inflammation. Drinking two glasses of chocolate skim milk/day may also help according to recent research from Spain.

Note: Whole foods are your best sources of vitamins and minerals - especially organically grown fruits and vegetables.

Some ataxias may be caused by certain micronutrient deficiencies, such as a deficiency in vitamin E. Such deficiencies are diagnosed by blood tests performed by your physician. If your ataxia is caused by a specific deficiency, then your physician may recommend treatment with larger doses of that micronutrient. However, if you have not been diagnosed with a specific deficiency, taking megadoses of any micronutrient may be harmful, rather than helpful and should not be undertaken without advice from your physician. Ataxia patients may wish to avoid herbal or other micronutrients unless your physician specifically recommends them for you to help with fatigue, which sometimes accompanies ataxia.

All brands of multivitamins and supplements are not created equal. Some brands have recently failed tests for purity, or potency. Price alone may not necessarily be a good indicator of quality. Most national store brands are rated as good quality. Many discount brands fail to meet quality standards. Look for GMPs (Good Manufacturing Practices) or U.S. Pharmacopeia standards-quality in a micronutrient supplement. ConsumerLab.com, Consumer Reports, or your physician can help in choosing a reliable brand.

WHAT ABOUT PRESCRIPTION AND OVER-THE-COUNTER MEDICATIONS?

Any prescription or over-the-counter drug that causes fatigue, tiredness, or weakness should generally be avoided by ataxia patients. Consult with your treating physician before taking any medications, especially those that you plan to take for an extended period.

WHAT IS GLUTEN ATAXIA?

Patients with celiac disease may develop cerebellar ataxia. Cerebellar ataxia in patients with celiac disease does not appear to be the result of poor nutrition, although celiac disease patients do often suffer from poor nutrition due to the inflammation of the lining of the gut tissue that prevents absorption of nutrients and vitamins. It is the allergy to gluten that is presently believed to be responsible for ataxia. A test for gliadin antibodies, which are proteins in the blood that react with gluten components, is necessary to determine if gluten allergy is a factor in your particular ataxia. Often, a strict gluten-free diet is recommended for people who have high gliadin antibodies and ataxia.

Because a gluten-free diet is a safe endeavor, trying the diet is risk-free. Before beginning this type of diet, consultation with a dietitian is useful to learn about the types of foods that contain gluten. Usually a trial of the gluten-free diet is recommended for at least six months, before reevaluation and possible continuation of the diet. Maintaining a gluten-free diet requires a continuous

commitment by patients and their families as gluten is found in many of our favorite foods.

HOW CAN THE NATIONAL ATAXIA FOUNDATION HELP?

The National Ataxia Foundation (NAF) is interested in all forms of hereditary ataxias and sporadic ataxia. The treatment and prognosis of ataxia, due to causes such as stroke or tumor, depends primarily on the treatment of the underlying cause. While little is understood of the underlying cause for the hereditary and sporadic ataxias with no cure available, NAF has been in the forefront for over 50 years funding promising worldwide research to find answers.

The National Ataxia Foundation is committed to education about ataxia, service to individuals affected with the various forms of ataxia and promoting research to find the causes, better treatments or a cure for ataxia. NAF can help by providing information for you, your family and your physician about ataxia.

If you have any additional questions or if we can be of any assistance, please contact:

The National Ataxia Foundation
2600 Fernbrook Lane Suite 119
Minneapolis, MN 55447-4752
(763) 553-0020
Fax: (763) 553-0167
Web: www.ataxia.org
Email: naf@ataxia.org

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ⁱ Adapted from Nadia Hamed, R.D. and Susan Perlman, M.D., "The Ataxia Diet" (2009); David Buchholtz, *Heal Your Headache: The 1-2-3 Program for Taking Charge of Your Pain* (New York: Workman Publishing, 2002); Siegel B. Love, *Medicine and Miracles: Lessons Learned about Self-Healing from a Surgeon's Experience with Exceptional Patients* (New York: Perennial, 1998); Timothy J. Maher, "Nutrition and Ataxia (March 22, 2009) at http://www.ataxia.org/pdf/2009_Nutrition_and_Ataxia.pdf.

ⁱⁱ If you take warfarin (a blood thinner), you should know that vitamin K or foods containing vitamin K can affect how the drug works. Ask your health care provider how much vitamin K or vitamin K-containing foods you should consume.

ⁱⁱⁱ *SCAI is a disorder resulting from the defective gene *Ataxin-1* misfolding of the protein produced by the gene. Dr. Nicolas Bazan of Louisiana State University found that the omega three fatty acid, docosahexainoic acid, protects cells from this defect.

^{iv} For each micronutrient, the Food and Nutrition Board of the Institute of Medicine establishes a recommended dietary allowance (RDA) or adequate intake (AI). For RDA/AI for older adults, see <http://lpi.oregonstate.edu/infocenter/olderadulteyedisorders.html>.

^v Taken from the University of Minnesota Ataxia Center Website <http://www.ataxiacenter.umn.edu/aboutataxia/sporadic/wheat/home.html>