Diet & Supplementation for Persons with Ehlers-Danlos Syndrome

You are not what you eat

http://ibbiology.wikifoundry-mobile.com/m/page/Explain%3A+why%3Adigestion+of+large+food+molecules+is+essential
“I have been diagnosed with Ehlers-Danlos Syndrome. Should I change my diet? Should I take any supplements?”

http://zebra.fishalaska.co/zebra-eats-what/

These questions should be easy to answer, right?
There is more to this statement.

That's why it does not end with an exclamation mark.

If I could say something easy like, "eat like a caveman," or "become a vegan," or "eat whatever you want, as long as it's non-GMO, organic, and ethically sourced" and take such-and-such proprietary blend of supplements, these questions about diet and supplementation could be answered in seconds.

Instead, I could be speaking for hours on this subject.

In my personal and professional experience, I believe I have been able to have the most positive impact on the quality of life of persons with EDS through educating them about nutrition.

I include “personal” in my experience, because I live this, and so does my family. I have EDS. I have children with EDS. I am passionate about this.
You have to start somewhere, so let’s start with the basics of food and supplements.

Think of our bodies as machines that require fuel as energy.

We derive our energy from our diet, and find ways to store or dispose of what we can’t immediately use.

From our diet, we also get the materials needed to build, maintain, and repair our machines and keep them running efficiently and reliably.

We need to think at a molecular level to understand how, nutrition fits in general into human health and nutrition fits in particular into the health of persons with EDS.

We are constantly breaking big molecules into smaller parts, and we reassemble the smaller parts into something we need, recycle or reuse them, or store or dispose of the smaller parts we don’t immediately want by digestion, absorption, metabolism, and elimination.

Whatever we consume is made entirely of molecules, and so are we.

By definition, molecules are neutrally charged arrangements of two or more ions held together by chemical bonds.

Molecules can be classified as “inorganic” or “organic.” (Keep in mind, at a molecular level, the term “organic” means something different than it means at the supermarket (or farmer’s market) - It has to do with whether the molecule has C with H, and O.

The terms “macronutrient” and “micronutrient” do not refer to the size of the nutrient molecule, but rather the amount of the nutrient required for optimal health.

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Organic and Inorganic Molecules we Consume
Everything we consume is a mix of these seven things
Water is really important - hence the slide has a lot of words.

Water accounts for about 60% to 70% of adult body weight.
Water in the body is either free or bound to other substances.

Obviously, we can drink water.

It is very important to realize:
All hydrogen from solid food is converted into wa-ter. (Water is a combination of H and O: H2O.)
A small amount of food hydrogen is excreted in the form of ammonia, urea, etc.
(Even foods which seem dry have H, and O is abundant in our tissues.)
Different foods yield different quantities of water.

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Water functions are listed, e.g.:
solvent for chemical reactions.
medium for physical processes.
important part of physiological processes (especially in the intestine, kidneys, circulation, urine, stool).
mechanical buffer (CSF)
lubricant (e.g., joints).
heat regulator (lost as sweat)
Does everyone really need eight glasses daily?

No.

(Statement is a giant myth. A lie.)

Just pull up snopes.com (the site that started out researching urban legends and has since grown into the oldest and largest fact-checking site on the Internet).

Dr. Heinz Valtin searched through existing literature and electronic databases and consulted with nutritionists and colleagues who specialize in water balance in the body to determine if there is any basis for the 8 glasses a day rule.

Dr. Valtin found no scientific evidence whatsoever to suggest that everyone needs to drink eight glasses of water a day. In fact, scientific studies suggest that you already get enough liquid from what you're consuming (according to appetite and thirst) on a daily basis!!!

Kidney specialists later expanded on Valtin’s efforts and explained that the 8-by-8 rule is a gross overestimate of any required minimum. Specifically, to replace daily losses of water, an average-sized adult with healthy kidneys sitting in a temperate climate needs no more than one liter of fluid to somehow enter the body.

The math goes like this: One liter is the equivalent of about four 8-ounce glasses of liquid. According to most estimates, that’s roughly the amount of water most Americans get in solid food.

Though many clinicians, social media, and public figures push the myth, and there is a huge industry providing us with celebrity-backed luxury versions of these vital inorganic molecules, most of us could cover our bare-minimum daily water needs through food, without drinking anything during the day.

IMPORTANT TAKE HOME POINT:

The average person does not need to drink much during the day. Persons with EDS may have specifically increased needs, and water needs must be considered in context, especially realizing the need for electrolyte balance. It is better to think in terms of “isotonic fluid intake” than “water intake”.

Aside from water, proteins are the most abundant kind of molecules in the body. They are formed when amino acids are bound together into long polymeric chains.

(See the lower left graphic illustrating formation of a peptide bond between two AAs.)

Ultimately, proteins may have very complex shapes and elaborate arrangements of polypeptide chains.

(Illustration of protein structure, and example of a lectin.)

Over 1000 amino acids have been chemically identified - some occurring naturally, some synthetically.

Why do we HAVE to consume protein?

Although we can burn it for fuel, carbs and lipids are generally used preferentially as fuel.

We need proteins for the specific AAs they supply.

Our genetic code is a set of instructions for proteins. That’s it. That’s what genes do. They encode proteins. Every gene indicates an exact sequence of “proteinogenic” amino acids to be bound together to make a specific protein.

So, our DNA makes proteins. We have to get the amino acids used to make proteins from somewhere.

Our cells are capable of making amino acids by combining simpler molecules.
So what foods do we get protein from?

http://ajcn.nutrition.org/content/59/5/1203S.long

“This short review ends with a list of series of myths and realities concerning the relationship between plant protein and human nutrition and a list of some nutritional issues of concern to the health professional and informed consumer.”

Big Picture:
Foods are described as
Complete vs Incomplete Proteins
high vs low in all essential AAs

Meat, products from milk, eggs, soy, and fish are sources of complete protein.

Proteins derived from plant foods (legumes, seeds, grains, and vegetables) are generally complete as well.

Certain traditional dishes, such as ... Cajun red beans (legumes) and rice ... combine legumes with grains to provide a meal that is high in all essential amino acids.

So - vegetarians and vegans have to have variety and combinations. Those who eat meat don't have to work so hard for variety to get their essential AAs, because their food ultimately did the work for them.

How much?
Take home: It varies.
Depends on size, level of activity, other health factors, such as metabolic state - anabolic (growth) vs catabolic (illness).
This is why labels don’t say the amount of protein in your food is a percentage of an established RDA. Instead, it tells you how many grams you are getting. It’s pretty much up to to figure out (or find help figuring out) how much you need.
Carbohydrates are single sugars (monosaccharides) or polymers (chains of monosaccharides) classified according to how many sugars (2, 3-9, >9).

(See graphic)

Note that sucrose is a disaccharide made of glucose and fructose.

Carbohydrates can have varying lengths and degree of branching of polymeric chains.
(e.g., Glycogen molecule)

Also: polyols are sugar alcohols.

Carbohydrates:
Normally used for short term energy storage.
Stored as glycogen in liver and muscle cells.
Contain 2 times less energy per gram than lipids.
More soluble in water than lipids, thus easier to transport in blood.

Realize that carbs can be converted to fat!!!
Figure 1. Carbohydrate classification and their main postprandial effects. SDS: slowly digestible starch; RDS: rapid digestible starch; RS: resistant starch.
From the Greek lipos for fat.

Main lipids of macronutrient importance: fatty acids, glycerolipids (esp. triglycerides), and sterol lipids. (Vitamin D is a sterol lipid.)

Lipids:
- Normally used for long term energy storage.
- Stored as fat in adipose cells.
- Contain 2 times more energy per gram than lipids.
- Less soluble in water than carbohydrates, thus harder to transport in blood.

Physiologically/metabolically important lipids which are not of nutritional importance as macronutrients include prenol lipids, glycerophospholipids, sphingolipids, saccharolipids, and polyketides. (Note that vitamins A, E, K are derived from prenol lipids.)

Special Mention: Lecithins are mixtures of glycerophospholipids in oils used to smooth food textures, emulsify or dissolve powders, homogenize liquid mixtures, or repel other materials (e.g. in non-stick cooking spray) and are common in the Western Diet and Modern Food Industry. Lecithins are a hot topic in nutrition.
Why did organic chemists make trans fats? To reduce spoilage, help withstand repeated heating (for frying), when people started to favor plant fats over animal fats.

Cis fats are less stable and more reactive than trans fats or saturated fats. Lipid peroxidation of fats breaks the long chains into shorter chains, which smell terrible.

The more cis double bonds, the more likely to go rancid. Nature solved this by combining antioxidants with unsaturated FAs.

But...
Why are trans fats bad? Carbon chains line up in a way that leads to rigid packing, e.g., plaquing.

Demonstrates importance of a whole food, rather than extracted ingredients. Should we be eating the oil or eating the olive?

Total fat
The dietary reference intake (DRI) for fat in adults is 20% to 35% of total calories from fat. That is about 44 grams to 77 grams of fat per day if you eat 2,000 calories a day. It is recommended to eat more of some types of fats because they provide health benefits. It is recommended to eat less of other types of fat due to the negative impact on health.

- Monounsaturated fat: 15%-20%
- Polyunsaturated fat: 5%-10%
- Saturated fat: less than 10%
- Trans fat: 0%
- Cholesterol: less than 300mg per day

https://my.clevelandclinic.org/health/articles/reducing-fat-intake
Something vital to one organism/species is not necessarily vital to another. For example, ascorbic acid.

Fat Soluble vs Water Soluble

Chronology
Ancient Egyptians knew eating liver helped with night blindness.
1747 James Lind discovered citrus foods helped prevent scurvy.
1898 Frederick Hopkins coined the term "accessory factors" (in addition to proteins, carbohydrates, and fats) necessary for functions of the human body.
1910 Umetaro Suzuki was first to isolate a vitamin complex.
1912 Kazimierz Funk isolated the same complex as Suzuki and suggested "vitamine" (from "vital amine").
1920 Jack Cecil Drummond proposed that the final "e" be dropped.
1929 Hopkins and Eijkman were awarded the Nobel Prize for Physiology or Medicine for vitamin-related discoveries.
1930s Vitamins moved from research to industry.

May be Conditionally Essential (e.g., Vitamin D)

Sterol Lipid: Vitamin D
Prenol Lipids: Carotenoids, Vitamin E, Vitamin K

There are also "vitamin-like" nutrients
No RDA, not essential to eat, but is physiologically essential
We can make it, so we don’t have to eat it
  e.g. choline

Regulation of supplements varies widely by country.
Food vs Drug

Most countries place dietary supplements in a special category under the general umbrella of foods, not drugs. As a result, the manufacturer, and not the government, has the responsibility of ensuring that its dietary supplement products are safe before
Inorganic

Amino acid chelates

Regulation

"In the context of nutrition, a mineral is a chemical element required as an essential nutrient by organisms to perform functions necessary for life.[1][2] Minerals originate in the earth and cannot be made by living organisms.[3] Plants get minerals from soil.[3] Most of the minerals in a human diet come from eating plants and animals or from drinking water.[3] As a group, minerals are one of the four groups of essential nutrients, the others of which are vitamins, essential fatty acids, and essential amino acids.[4] The five major minerals in the human body are calcium, phosphorus, potassium, sodium, and magnesium.[1] All of the remaining elements in a human body are called "trace elements". The trace elements that have a specific biochemical function in the human body are iron, cobalt, copper, zinc, manganese, molybdenum, iodine, and selenium.[5]"
A grey zone...

All images from Wikipedia
caffeine
BHT
Blue Dye # 1
curcumin
quercetin

Some things in the category are thought to be highly beneficial, while others are considered toxins to be avoided.

{nucleic acids
All life on earth is said to be composed of four types of organic molecules (i.e. proteins, carbohydrates, lipids, nucleic acids) in addition to water, minerals, and inorganic molecules (e.g. salts). We can make nucleic acids, so we do not have to eat them.}
The Europeans are way ahead of us on this... they consider the term "Superfood" a marketing tool and regulate the use of the term.

[What are functional foods? they scare me... see wikipedia FOSHU]
NO!

No evidence has been established to tell us what to include or exclude with EDS.

"You can't just eat your way out of EDS!!"
Fibers promote flexibility, fill space, allow for stretch and recoil.

Microfibrils are needed for building and support of other fibers.
Not all forms of EDS are proven to be due to mutations in genes encoding collagen. Faulty collagen vs. faulty gene products regulating or interacting with collagen.

Collagen Assembly
- Triple helix of coiled protein chains made of amino acids
- A high proportion of glycine, proline, and lysine
- Requires vitamin C for hydroxylation of procollagen molecules

Collagen Digestion
- Catabolized first into smaller peptide chains
- Ultimately catabolized into amino acids
- Assembled into new peptide chains or catabolized via Krebs Cycle

No established research or clinical experience has proven that collagen supplementation is helpful for persons with EDS! Theoretically, a diet adequate in glycine, proline, lysine, and vitamin C (or supplementation) would support collagen biosynthesis.

Bottom Line:
People who make the statement that they feel much better on collagen supplements would probably feel similar if they ate foods rich in the nutrients contained in the supplement!!! (This may be the appeal of bone broth.)
So... why should persons with EDS bother eating in a specific way or taking supplements?

The thing is... EDS doesn't exist as a disorder in isolation.
Joint Hypermobility Syndrome

Asma Fikree, BM BCh, MA, MRCP, Qasim Aziz, PhD, FRCP, Rodney Graeme, CBE, MD, FRCP*,

KEYWORDS

• Hypermobility • Hypermobility syndrome • Ehlers-Danlos syndrome • Dysautonomia
• Functional gastrointestinal disorder

KEY POINTS

• Joint hypermobility syndrome is a common, heritable disorder of connective tissue that is frequently overlooked.
• It is almost certainly identical to the Ehlers-Danlos Syndrome, hypermobility type.
• It is not a trivial articular problem occurring in healthy individuals; it is now recognized as a multisystemic disorder and a major source of chronic widespread pain, dysautonomia, and gastrointestinal dysmotility. It is a neglected area within rheumatology.

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Joint Hypermobility Syndrome

"Autonomic dysfunction is a frequently occurring feature of EDS. In one series it was identified (by the Brighton criteria) in 78% of patients with EDS compared with 2.1% of controls. The most common type of dysautonomia seen in EDS is postural tachycardia syndrome (PoTS)... Symptoms include palpitations, orthostatic intolerance (dizziness, presyncope, or syncope on standing), headache, impaired concentration, forgetfulness, irritability, fatigue, and heat intolerance."

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Joint Hypermobility Syndrome

“Patients with [EDS] attending a hypermobility clinic had significantly more GI symptoms compared with age-matched and sex-matched controls (37% vs 11%). The most common GI symptoms were nausea, abdominal pain, constipation, and diarrhea. It was thought that dysautonomia was one mechanism by which this may occur and since then it has been shown that PoTS is associated with GI symptoms such as nausea, reflux, bloating, constipation, and diarrhea. Thus it seems that [EDS], autonomic symptoms, and GI symptoms are linked, although the exact mechanism for the association is unknown.”
Joint Hypermobility Syndrome

“In a study of 21 patients with EDS, 87% of patients had GI symptoms, most commonly dyspepsia (67%), gastroesophageal reflux (57%), recurrent abdominal pain (62%), alternating constipation and diarrhea (33%), and abdominal hernias (5%). Furthermore, the incidence of GI symptoms increased with age, and older patients with EDS were more likely to have GI symptoms than their younger counterparts.”

- It is not a trivial articular problem occurring in healthy individuals; it is now recognized as a multisystemic disorder and a major source of chronic widespread pain, dysautonomies, and gastrointestinal dysmotility. It is a neglected area within rheumatology.

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High prevalence of Food Allergies in Patients with Ehl…

Ehlers-Danlos syndromes (EDS) are a heterogeneous group of hereditary disorders of connective tissue that are characterized by joint, skin, and vascular abnormalities.

Complete physical and medical histories were obtained from 95 patients with hypermobile, classical, and vascular EDS enrolled in the National Institutes on Aging Protocol 2003-086. “Clinical and Molecular Manifestations of Heredity Disorders of Connective Tissue.”

We found a high prevalence of food allergies in patients with EDS (14%) when compared with the general population (P<0.001). We also found a significantly higher incidence of gastrointestinal manifestations in our cohort when compared with the general population (P<0.001). The presence of food allergies also seems to correlate with gastrointestinal dysfunction in some patients. Of the patients who reported constipation, irritable bowel syndrome, gastroesophageal reflux disease, and/or chronic abdominal pain, many also reported having a food allergy (40%, 42%, 17%, and 20%, respectively).

Collagen abnormalities may cause mucosal lesions, altering tissue integrity and increasing the chance of larger proteins crossing the mucosal barrier and creating an immunogenic response. Multiple studies have correlated eosinophilic gastrointestinal disorders, allergic responses that fall in between IgE and Th2-type responses that are mediated by IL-5 and other eotaxins, with classic mast cell tissue degranulation, producing gastrointestinal disorders similar to those seen in our patients.

Understanding the mechanisms associated with food allergies in patients with EDS may aid in development of effective treatments.
High prevalence of Food Allergies in Patients with Ehlers-Danlos Syndromes.
H. Zhang1, B.F. Gorwold, L. Sliper2, M. Lovelace1, C.A. Francemen1, N.B. McDonnel1, P. Gustafson1
1) LCL, NIAID, Baltimore, MD; 2) GBMC, Baltimore, MD; 3) IUH, South Bend, IN.

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Program Nr: 21352 from the 2007 ASHG Annual Meeting

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Ehlers-Danlos syndrome hypermobility type is associated with rheumatic diseases

Kyle R. Rodgers1, Jiang Gui1,2,*, Mary Beth P. Dinulos1,2 & Richard C. Chou1,2

We retrospectively analyzed electronic medical records of patients with Ehlers-Danlos Syndrome hypermobility type (HEDS), including demographic information, workup, rheumatological diagnoses in order to determine its association with rheumatological conditions. HEDS patients were stratified according to level of workup received (no additional work (physical exam only): NWU, limited workup: LWU, comprehensive workup: CWU). HEDS patients were predominantly female (254/494). The percentage of patients with at least one rheumatological condition was significantly correlated with level of workup (NWU: 9.2%, LWU: 23.3%, CWU: 67.1%; p-value < 0.0001). The HLA-B27 antigen was more prevalent (p-value < 2.2 x 10^-7) in the CWU HEDS patients (23.9%) than in the general population of the United States (6.1%). HEDS with CWU were associated with more rheumatological conditions (i.e. psoriasis, ankylosing spondylitis, rheumatoid arthritis, fibromyalgia) than those with NWU or LWU. In conclusion, HEDS is associated with complicated rheumatological conditions, which are uncovered by comprehensive workups. These conditions require different clinical management strategies than HEDS, and left untreated could contribute to the pain or even physical disability (i.e., joint erosions) in HEDS patients. While the mechanisms underlying these associations are unknown, it is important that all HEDS patients receive adequate workup to ensure a complete clinical understanding for the best care strategy possible.
Ehlers-Danlos syndrome hypermobility type is associated

“We found that several structural deformities or deficiencies (i.e. club foot, hereditary angioedema, primary hypogammaglobulemia), non-inflammatory diseases (fibromyalgia, erythromelalgia), and autoimmune/inflammatory diseases (psoriasis, PsA, AS, RA, inflammatory eye disease, autoimmune thyroiditis, SLE, Crohn’s disease, pernicious anemia, and TRAPS) were significantly more prevalent in the CWU HEDS population than in the general population of the US.”
Ingrid Cheung, Peter Vadas, MD, PhD; St. Michael’s Hospital, Toronto, ON, Canada.

RATIONALE: Patients with postural orthostatic tachycardia syndrome (POTS) and hypermobility often describe symptoms suggestive of mast cell activation. Herein, we describe a new, unique phenotype, characterized by the co-segregation of three disorders: POTS, Ehlers-Danlos syndrome (EDS) and mast cell activation syndrome (MCAS).

METHODS: Participants with diagnoses of POTS and EDS were recruited from throughout North America through a patient support group and evaluated by questionnaire and supporting documentation. A formal diagnosis of POTS by a cardiologist included confirmation via tilt-table test. A formal diagnosis of EDS required assessment by a dermatologist, a Beighton score of ≥5/9 and a diagnostic skin biopsy. A questionnaire for MCAS was based on diagnostic criteria and validated symptoms as reported by Akas, Valenti and Metcalfe (2010).

RESULTS: 15 participants completed questionnaires with required documentation. All eligible participants were female. 12 of these people had formal diagnoses of POTS (80%), 9 were diagnosed with both POTS and EDS, 6 of 9 patients with both POTS and EDS had validated symptoms of a mast cell disorder (66%), suggestive of MCAS.

CONCLUSIONS: From these pilot data, it appears that a mast cell disorder may frequently co-segregate with POTS and a collagen disorder such as EDS.
A New Disease Cluster: Mast Cell Activation Syndrome, Postural Orthostatic Tachycardia Syndrome, and Ehlers-Danlos Syndrome

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“From these pilot data, it appears that a mast cell disorder may frequently co-segregate with POTS and a collagen disorder such as EDS.”
“Previously, we described subjects with dominantly inherited elevated basal serum tryptase levels associated with multisystem complaints including cutaneous flushing and pruritus, dysautonomia, functional gastrointestinal symptoms, chronic pain, and connective tissue abnormalities, including joint hypermobility. Here we report the identification of germline duplications and triplications in the TPSAB1 gene encoding α1-tryptase that segregate with inherited increases in basal serum tryptase levels in 35 families presenting with associated multisystem complaints. Individuals harboring alleles encoding three copies of α1-tryptase had higher basal serum levels of tryptase and were more symptomatic than those with alleles encoding two copies, suggesting a gene-dose effect.”
EDS and comorbid issues exist in complex interrelationships, and we may be getting closer to determining some of the pathophysiology underlying the interrelationships.
The diet and supplement guidelines I discuss with my patients are intended specifically to benefit patients by helping to minimize occurrence or exacerbation of THE OTHER ISSUES most commonly arising in tandem EDS while supporting basic human nutritional needs.

It is important to realize that general guidelines must be tailored to individual needs, and challenges or barriers to adherence to such guidelines must be recognized and addressed as best possible.

Persons with Ehlers-Danlos need to take responsibility for addressing the things they can control!!!

This lecture includes diet and supplements. Lifestyle is covered in other lectures, as are things for which patients must rely upon clinicians, such as prescription medications, therapies, modalities, equipment, and surgical or otherwise invasive interventions.

Although EDS has been defined by articular hypermobility, EDS often occurs in tandem with extra-articular issues:

{the big 3...}
autonomic dysfunction
GI dysfunction
immune dysfunction (e.g. allergies, autoimmune disorders, and dysregulation at a cellular level such as eosinophilic or mast cell disorders)

{Do secondary mitochondrial disorders deserve mention here?}
DIETARY GUIDELINES FOR PERSONS WITH EHLERS-DANLOS SYNDROME: EAT TO MINIMIZE AUTONOMIC DYSFUNCTION

Water:
- Drink lessens fluids in synovial and support microvascular vessels.
- Avoid excessive amounts of hypertonic fluids.

Prescription:
- What about intake of proteins high in cysteine, e.g., procarnosine: long chain?
- How do foods of phenylalanine and tyrosine affect dysautonomia?

Carbohydrates:
- Be low-glycemic load foods with low glycemic index.
- Limit “bad carbs”: concentrated sugars, rapidly digested starches.
- Watch about sorbitol (e.g., a phenylalanine derivative) as a major substrate.

Lipids:
- Limit “bad fats” which contribute to insulin resistance.

Vitamins:
- POT5 occurs with significant frequency in persons deficient in B12.

Minerals:
- Uremic salts.
- Magnesium acts as an alpha adrenergic blocker.

Other Things:
- Maintain ketone levels.
In with the good, out with the bad!

GI goal is to improve absorption (in with the good), preserve intact mucosal barrier for healthy immune function (keep the bad out), and carry away digestion-related waste (send the bad out).
Promote normobiosis.

let the gut flora do some of the work for you!!!
you scratch their back, they’ll scratch yours

(See: http://www.bengmark.com/sites/default/files/110.%20Microbiota,%20immune%20%20....Pharmacological%20Research%202012.pdf)

Over 100 trillion organisms occupy the human gut (e.g., bacteria, archea, fungi, protozoa). Over 1000 species identified so far. Over 90% of the cells within our body are microbial! Our microbiota have hundreds of times more genes than us.

Role of the Gut Biome
ferment undigested carbohydrates
provide short chain fatty acids as energy
enhance lipid metabolism
fat-soluble vitamin A, D, E, and K absorption
assist in absorption of minerals (e.g., Ca, Mg, Fe)
synthesize nutrients (e.g., B vitamins, vitamin K, folate, biotin)
metabolize bile acids, sterols, and xenobiotics
ferment non-digestible dietary residue and mucus
support / regulate epithelial and lymphoid function
affect the production of neurotransmitters by gut tissue

| DIETARY GUIDELINES FOR PERSONS WITH EHLERS-DANLOS SYNDROME: HOW TO FOSTER NORMOBIOSIS |
|---|---|
| Inclusions and Increases | Exclusions and Decrease |
| Consume probiotics. | Avoid refined carbohydrates. |
| e.g., miso, FOS, XOS, GOS, beta-glucans, chicory root, Jerusalem artichoke, dandelion greens, goji, leeks, onion, asparagus, bananas. | Limit daily intake of fructose <25g/day. |
| Consume prebiotics. | Eliminate sugar alcohols (e.g., xylitol, sorbitol). |
| e.g., kefir, yogurt, miso, tempeh, kimchi, asparagus. | Eliminate artificial sweeteners (e.g., aspartame). |
| Increase intake of antioxidants and fiber. | Minimize intake of saturated fats. |
| Keep diet rich in. | Avoid heavily fried, grilled, sautéed, and insulfed foods. |
| Fresh greens and vegetables, and certain fruits. | Reduce intake of cured meats. |
| ancient grains. | Limit alcohol consumption. |
| buckwheat, amaranth, chia, millet, quinoa, sorghum, farro. | Eliminate or minimize cassava, gluten, and soy. |
| beans, peas, chickpeas, lentils, nuts and almonds. | Eliminate polypharmacy where possible. |
| Supplement vitamin D and omega FAs. | In the future, will be guided by the dysbiosis in EDS be an accepted / approved clinical indication for ‘local transplant’ |

https://commonfund.nih.gov/hmp/
DIETARY GUIDELINES FOR PERSONS WITH EHLERS-DANLOS SYNDROME: EAT TO MINIMIZE IMMUNE DYSFUNCTION

Recognize even minor food intolerances, true food allergies, cell-mediated reactions (e.g., eosinophilic esophagitis, mast cell disorders), or specific antigen-induced immune reactions (FPIES) when they exist, and adjust diet accordingly!

- This includes exploring cross-reactivity (e.g., latex cross-reactivity manifesting as intolerance to avocado, banana, kiwi, apple, carrot, potato, tomato, etc.)

Consider use of a food journal to recognize reactivity to things in diet.

Consider proactive avoidance of notoriously inflammatory foods (e.g., wheat, eggs, non-cultured dairy, corn).

Strive for normobiosis, as it assists in support/regulation of epithelial and lymphoid function.

Address comorbid dysautonomia and GI dysfunction.
Common deficiencies often seen in persons with EDS (or known to exacerbate symptoms associated with EDS and the secondary conditions arising from EDS)

- Mag (and B6)
- VitD
- VitC
- VitB12

Deficiencies must be addressed. Where possible, get vitamins and minerals from food!

Also mention:
- Parenteral repletion.
- RDAs VitC is frequently dosed higher than USRDA

If you are taking a supplement by prescription or under advice of a clinician, it is not considered a "drug", but its dose may be higher than the recommended allowances established by regional governing bodies such as the FDA. (We might HEAR something like "prescription strength vitamin D3")

Also - Particularly challenging for some patients to afford as supplements
DIETARY GUIDELINES FOR PERSONS WITH
EHLERS-DANLOS SYNDROME:
RESPECT HIGHLY INDIVIDUALIZED NEEDS

A Tangled Web!

- Dysautonomia can cause or aggravate not only GI
dysfunction (as “Fight or Flight” overpowers “Rest and
Digest”), but also immune dysfunction.
- Similarly, GI dysfunction can cause or aggravate immune
dysfunction and dysautonomia.
- ... and immune dysfunction can cause or aggravate
dysautonomia and GI distress.
- Each individual is unique. For example:
  - Allergies and intolerances which limit choices.
  - nightshade intolerance
  - MTHFR polymorphism
  - level of compliance

This is where it gets challenging and often requires a truly
multi-disciplinary approach!
In the 19th century and well into the 20th century coal miners would traditionally take canaries in cages down into the mine with them. The birds would act as an early warning system for carbon monoxide gas. When the canary stopped singing the miner would know that he had to escape the chamber he was in.

This particular yellow canary ... was obviously a favoured pet as well as a working bird. Inscribed with the legend: ‘In Memory of Little Joe. Died November 3rd 1875. Aged 3 Years’


“In the 19th century and well into the 20th century coal miners would traditionally take canaries in cages down into the mine with them. The birds would act as an early warning system for carbon monoxide gas. When the canary stopped singing the miner would know that he had to escape the chamber he was in.

This particular yellow canary on the top photo was obviously a favoured pet as well as a working bird. Inscribed with the legend: ‘In Memory of Little Joe. Died November 3rd 1875. Aged 3 Years’
“Persons with Ehlers-Danlos Syndrome are the canaries in the Western Diet and Modern Food Industry Coal Mines.”

— Heidi Collins, MD


{As persons with EDS we are the canaries in that Western Diet modern food industry coal mine - or the modern world's entire "better living through chemistry" coal mine. That would be an even bigger lecture!!!}

The mine conditions have gone downhill.
I don’t intend to reinvent the wheel. There is a reason these books are so successful.

The content covered in In Defense of Food applies to ALL HUMANS - INCLUDING PERSONS WITH EDS

It is not mere opinion - EXTENSIVELY SOURCED INCLUDING PEER-REVIEWED LITERATURE.
The food industry has been heavily influenced by nutritionism and economics.

"Once, food was all you could eat, but today there are lots of other edible foodlike substances in the supermarket.

The story of how the most basic questions about what to eat ever got so complicated reveals a great deal about the institutional imperatives of the food industry, nutritional science and — ahem — journalism, three parties that stand to gain much from widespread confusion surrounding what is, after all, the most elemental question an omnivore confronts.

So depending on the reigning nutritional orthodoxy, the avocado might be either a high-fat food to be avoided (Old Think) or a food high in monounsaturated fat to be embraced (New Think). The fate of each whole food rises and falls with every change in the nutritional weather, while the processed foods are simply reformulated."
THE GENOME, THE EPIGENOME, AND INHERITANCE

**Genome:** the complete assembly of DNA that makes each individual unique.

**Epigenome:** chemical compounds and proteins that can “mark” DNA (without changing the DNA sequence) to direct such actions as turning genes on or off in certain cells.

- Methyl groups directly mark DNA by attaching to specific bases to turn genes “on” or “off.” (Methylation)
- Histone proteins provide spool-like structures for DNA to coil around, and tags are attached to histones which indicate whether larger regions of DNA should be used or ignored. (Histone Modification)

Marks are sometimes passed on from cell to cell as cells divide.

Marks can be passed down from one generation to the next.

The Key to Epigenetic Inheritance: Much of the epigenome is reset when parents pass their genomes to their offspring, however, under some circumstances, some of the chemical tags on the DNA and histones of eggs and sperm may be passed on to the next generation.

https://www.genome.gov/27532724/epigenomics-fact-sheet/

https://learn.genetics.utah.edu/content/epigenetics/
"The researchers ... cited the Children's Health Study from Southern California, which reported that grandmaternal smoking during pregnancy increases the risk of asthma in grandchildren regardless of whether the mother smoked or not. Based on those findings, the researchers conclude that environmental factors experienced during pregnancy will affect not only the child in utero but also future generations of the same family. They say this multi-generational transmission could explain why 98% of inherited human diseases are unaccounted for by the prevailing view of genetic trait transmission, known as Mendelian genetics."

https://learn.genetics.utah.edu/content/epigenetics/
So if a pregnant mother's diet can affect the child's epigenetic outcome, can dad's diet do the same?
No two people are alike, and thus there is no single "EDS Diet" or single set of specific recommended daily allowances of vitamins or minerals which could possibly apply as the single definitive guideline to all persons with EDS.

We have to work not only on what our dietary choices are, but we need to optimize our nutritional status and metabolic health by addressing any factors we can control which affect digestion and absorption, while also addressing/minimizing comorbid issues.

It takes time! Your body needs to be in a condition able to absorb nutrients. If you are ill as a result of a poor diet, and you start making the right food choices, your health will NOT just do a 180 overnight - it takes time for the desired changes to occur in your body, especially when chronic malabsorption and immune dysregulation have been at play.

Take home,
   • It's not all your fault. Things happened before you were even conceived...
   • It's not all about you. We have an obligation to diagnose EDS early, and we need to ensure dietary habits and needs for supplementation are implemented early not only to benefit you, but to benefit generations to come.