

Nutrition and Myositis

What we know
(and still need to learn)

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Talk Outline

- ✿ Eating healthy in general
- ✿ Nutritional abnormalities in chronic disease
- ✿ Specific supplements and diets related to myositis

“It’s not rocket science”

- ✿ Eat healthy foods
- ✿ Eat moderate portion sizes
- ✿ Eat a varied diet
- ✿ Enjoy your meals
- ✿ Involve yourself in meal preparation

We are so much more than our myositis

- ✿ We are what we are thanks to our genes and our environment
- ✿ We do have control over some things
- ✿ We unfortunately can also get:
 - ✿ Diabetes
 - ✿ Heart disease
 - ✿ Cancer
 - ✿ Alzheimer's

Anti-oxidants

- ✿ Decrease oxidative stress, especially in heart disease and cancer
- ✿ Water-soluble, e.g. vitamin C
- ✿ Fat-soluble, e.g. carotene, vitamin E, CoQ10
- ✿ Found in vegetables, fruits, beans, nuts, herbs and spices
- ✿ Supplements are not as effective as whole foods and may even be harmful

Anti-oxidants

- ✿ Foods richest in antioxidants:
 - ✿ Beans, like red, kidney and pinto
 - ✿ Artichoke hearts
 - ✿ Berries
 - ✿ Apples and plums
 - ✿ Green tea
 - ✿ Dark chocolate!!

✿ Balance!!

- ✿ Over-eating of one type can result in mineral binding (iodine, calcium, zinc, iron)
- ✿ Binding can occur from:
 - ✿ Oxalates (cocoa, spinach),
 - ✿ Phytates (legumes, whole grains)
 - ✿ Tannins (tea, beans, cabbage)

Eat Your Veggies (and Fruits)



- ✿ All vegetables provide good nutrients and fiber with some exceptions:
- ✿ Corn and white potatoes have a high-glycemic index
- ✿ Other veggies can nearly be eaten in unlimited quantities with a healthy preparation
- ✿ Fruit: “One is a serving; two or more is dessert”
- ✿ Juice: how many apples or oranges would you eat?



Carbohydrates: Our love-hate relationship

- ✿ Think of these foods as “CARBAGE”
- ✿ Sugar really can be addictive; eliminating it causes decreased desire
- ✿ Learn to lower your glycemic load
- ✿ Avoid all processed foods
- ✿ “Fight the white”: Grains should be whole-grain, such as bulgur wheat, brown rice, quinoa



Carbohydrates: Our love-hate relationship

- ✿ No high-fructose corn syrup (HFCS)!!
 - ✿ Long-term effects similar to alcohol due to its metabolism by the liver
 - ✿ May increase one's risk of *nonalcoholic fatty liver disease (NAFLD)*.
- ✿ Avoid soda:
 - ✿ Sugary ones have the HFCS
 - ✿ But artificial sweeteners in diet sodas change the gut microbiome
 - ✿ Both contain phosphoric acid

And then there are the fats...

- ✿ Our society has an imbalance of omega-6 and omega-3 fatty acids, also called PUFAs (polyunsaturated fatty acids)
- ✿ Major factor responsible for obesity epidemic and heart disease
- ✿ Omega-3 = anti-inflammatory
- ✿ Omega-6 (in excess) = pro-inflammatory
- ✿ Early human diet was a 1:1 ratio of 6 and 3 PUFAs; now it is 10:1-15:1 or higher

Fatty Acids: *Omega-3*

- ✿ Alpha-linolenic acid (ALA): flaxseeds and walnuts richest sources as well as canola
- ✿ Body converts ALA → EPA → DHA (men less than women, all of us less with age)
- ✿ Major sources EPA and DHA: oily fish, enriched eggs
- ✿ Supplements: fish oil has EPA and DHA; algal and fungal sources have DHA

Fatty Acids: *Omega-3*

- ✿ Can decrease production of inflammatory molecules, including TNF-alpha
- ✿ May increase the efficacy of anti-TNF-alpha therapy
- ✿ Eating oily (wild-caught) fish 1-3 times a week may be enough
- ✿ Fish or krill oil (distilled) 2-3 grams per day as supplement as alternative
- ✿ Avoid if on blood thinners, upcoming surgery

Fatty Acids: *Omega-6*

- ✿ Food sources: linoleic acid (LA)
 - ✿ Safflower, sunflower, grapeseed, soy, corn
- ✿ Supplements: gammalinolenic acid (GLA)
 - ✿ Considered an anti-inflammatory agent; possibly helpful for autoimmune disorders
 - ✿ Borage, black currant, & evening primrose oils
 - ✿ Choose borage oil without *pyrrolizidine alkaloids*, which may damage the liver; also use with caution if on blood thinners

Fatty Acids: *Omega-7*

- ✿ Conjugated linoleic acids (CLA)
- ✿ Made by gut bacteria in ruminant animals (sheep, goats, cows, kangaroo!)
- ✿ Anti-cancer*, anti-RA/lupus, anti-abdominal fat deposits, promotes muscle growth, opposes stress-induced cortisol
- ✿ Grass-fed animals have 300-500% more CLA than grain-fed
- ✿ Caution if overweight: may cause insulin resistance

*(except HER2+ breast cancer)

What fats are good to eat?

✿ Cooking oils:

- ✿ Olive (use regular; save pricier extra-virgin for dressings)
- ✿ Walnut
- ✿ Flaxseed
- ✿ Expeller-pressed organic canola, sunflower or safflower
- ✿ Coconut (medium chain saturated fat)

What fats are good to eat?

✿ Food sources:

- ✿ Fatty fish (salmon, sardines, herring)
- ✿ Pasture-fed beef and pork
- ✿ Omega-3 fortified eggs
- ✿ Hemp, chia seeds and flaxseeds

✿ Nuts, especially walnuts, cashews, almonds

✿ And....a weed??

Purslane

- ✿ You probably have it in your yard
- ✿ More omega-3 fatty acids (ALA) than any other leafy plant
- ✿ Use as you would spinach
- ✿ Can be eaten raw, stir-fried, in soups



What fats not to eat?

- ✿ Simple: Avoid any partially hydrogenated fats
- ✿ Avoid corn, cottonseed, vegetable, palm kernel, safflower* and sunflower* oils
- ✿ Avoid fried foods: potential for *trans*-fats or toxic compounds with high heat

*unless expeller-pressed, organic

Anti-Inflammatory Diet

- ✿ Avoid processed foods: eat “whole foods”, the way nature intended it
- ✿ Avoid sugar, high-fructose corn syrup
- ✿ Eat lean protein, more fish, less animal protein, except free-range poultry, grass-fed beef or pork in moderate amounts

Anti-Inflammatory Diet

- ✿ Remember those vegetables
- ✿ Broth-based soups
- ✿ Green, white or oolong tea
- ✿ Chocolate (at least 70% cocoa)
- ✿ Consider eating organically

Positive Effects of Anti-Inflammatory Diet

- ❖ In a 2007 study, Rose Mary Istre found those with myositis who followed an AID over 12 weeks had improved:
 - ❖ Ease of routine activities
 - ❖ Severity of depression
 - ❖ Grip, arm and leg strength measurements





Consider Eating Organic

- ✿ Unclear if pesticides, etc. are harmful for (or trigger??) autoimmune disease
- ✿ Organic foods are also non-genetically-modified (non-GMO)
- ✿ GMO foods can have animal genes inserted into fruit and vegetable genes
- ✿ While GMO foods may have the same *nutritional* value, it is not known if long-term ingestion is safe.

The “Dirty Dozen”: “Buy organic or not at all”

🌿 Peaches

🌿 Apples

🌿 Bell peppers

🌿 Celery

🌿 Nectarines

🌿 Strawberries

🌿 Carrots

🌿 (Lettuce)

🌿 Cherries

🌿 Kale

🌿 Grapes

🌿 Blueberries

🌿 Spinach

🌿 Potatoes

🌿 Grapes
(imported)

The “Clean Fifteen”: Lowest in Pesticides

- ✿ Onions
- ✿ Avocados
- ✿ Sweet corn
- ✿ Pineapple
- ✿ Mango
- ✿ Asparagus
- ✿ Sweet peas
- ✿ Sweet potato
- ✿ Kiwi
- ✿ Cabbage
- ✿ Eggplant
- ✿ Papaya
- ✿ Watermelon
- ✿ Broccoli
- ✿ Tomatoes

Salt

- ✿ Daily salt intake should be 1200 mg (over 70 years) – 1500 mg (under 50)
- ✿ One McDonald's bacon, egg, cheese biscuit has 1250 mg of salt
- ✿ 77% of sodium comes from restaurant and processed foods (5% home-cooked, 6% added at table, 12% naturally-occurring)

Salt

- ✿ Recent studies found that mouse and human cells cultured in high-salt conditions produced more of the immune T_H17 cells than those grown in normal conditions.
- ✿ Some forms of autoimmunity have been linked to overproduction of T_H17 cells, a type of helper T cell that produces an inflammatory protein called interleukin-17.

Salt

- ✿ The rising popularity of fast food -- laden with up to *100 times* as much salt as similar home-prepared meals -- has accompanied an increase in autoimmune diseases.
- ✿ Particularly relevant would be for patients with MS and psoriasis, which both are strongly influenced by TH17
- ✿ Salt = sodium chloride; “*fancy*” and sea salts still contain sodium

Body Mass Index and Medication Effects

- ✿ Increased BMI is associated with increased inflammation
- ✿ Studies in patients with inflammatory conditions such as asthma and rheumatoid arthritis show decreased results from medications, such as steroids, adalimumab, etanercept, and infliximab

Daien CI, *Mediators Inflamm*, 2014

So remember...

✿ Eat the rainbow!

✿ Include lots of foods - whole and fresh - that are red, orange, green, blue and yellow

✿ “Fight the white”: Avoid...

- ✿ Added salt and processed foods
- ✿ White sugar (or too much of any kind, really)
- ✿ White potatoes
- ✿ White rice
- ✿ White bread
(or maybe all wheat bread....)



Curcumin

- ✿ Active ingredient in turmeric (think curry and mustard)
- ✿ Inhibits inflammation with interest in cancer, inflammatory disease and Alzheimer's
- ✿ 2007 study in mice: blunting of CK increase with exercise-induced muscle damage
Davis J. Am J Physiol Integr Physiol 2007;292:R2168
- ✿ 2008 study in mice improvement with muscular dystrophy
Pan Y. Mol Cells. 2008;25(4):531

Curcumin

- ✿ Seems to accumulate best in colon
- ✿ Holds promise for GI-related conditions
- ✿ Curcumin is very poorly absorbed
- ✿ Doses less than 4 grams per day were not detected in serum in human clinical studies
- ✿ New formulations, such as nanoparticles are being investigated to increase its availability

Curcumin

- ✿ Need to combine with piperines (black pepper extract) to improve absorption
- ✿ May increase bleeding in those taking drugs like coumadin
- ✿ Because of its inhibitory effect on COX-1 and COX-2, might increase risk of cardiac disease
- ✿ Have a good lipid profile as safeguard

Coenzyme Q10 (ubiquinone)

- ✿ Reduction in CoQ10 could cause abnormal mitochondrial dysfunction
- ✿ Statins lower CoQ10, but studies have not shown that supplements increase levels
- ✿ “The present evidence does not support [its] supplementation in statin-induced myopathy.”

Schaars C and Stalenhoef, 2008 Current Opinion in Lipidology

The problem with CoQ10

- ✿ No great data for its use in myositis (IIM)
- ✿ As we age, CoQ10's absorption, biosynthesis and conversion to ubiquinol decreases
- ✿ Ubiquinol form is better absorbed and probably more effective
- ✿ Does it matter? (Serum vs. tissue levels)

Coenzyme Q10

- ✿ Interest in cardiac, neurologic and **periodontal** diseases
- ✿ 150 mg daily of ubiquinol used in studies
- ✿ Choose ubiquinol form instead of ubiquinone for better absorption
- ✿ Avoid if on coumadin

Vitamin D

- ✿ Clearly seems to have a role in *preventing* autoimmune disease (patients with DM/PM, RA, SLE, etc. found deficient)
- ✿ Its role in *treatment* less clear
- ✿ However, supplementation in statin-induced myositis patients reversed symptoms in 87% of 150 patients studied

Glueck C. Current Med Res Opin 2011;27:1683

Vitamin D

- ✿ Important to support bone health, mental health, infection control
- ✿ Especially important for those avoiding the sun and with dark skin
- ✿ Decreased by steroid use
- ✿ Blood levels above 30 considered adequate; 40-45 may be ideal; higher levels do not lead to longer life

Vitamin D

- ✿ Treatment for deficiency: 2000 IU/day of vitamin D₃ or 50,000 IU/week of vitamin D₂
- ✿ Roughly 100 units/day raises vitamin D level by 1 ng/ml (or 1000 U/day raises level by 10); double dose needed for overweight patients
- ✿ Recheck level after 6 weeks of supplement

Folate (folic acid or B9)

- ✿ Important for anyone taking *methotrexate* to decrease its side effects:
 - ✿ Decreased white blood cells, GI symptoms, hair loss, liver and lung toxicity
 - ✿ Supplement as 1-2 mg daily (Rx)
 - ✿ Controversial if should avoid taking on same day as methotrexate (possibly less effective)
- ✿ Have adequate vitamin B₁₂ intake since symptoms of its deficiency can be masked by folate supplementation
 - ✿ Good sources of B₁₂: fish/shellfish, beef, eggs

Probiotics

- ✿ Observed increase in autoimmune disease in those with decrease in beneficial bacteria
- ✿ Autoimmunity associated with “leaky gut”, allowing antigens to enter and stimulate the immune system
- ✿ Those with altered gut flora have slower metabolism, higher risk for obesity

Probiotics

- ✿ In many autoimmune conditions, improving intestinal inflammation improves symptoms
- ✿ A normal “*human biome*” or “*microbiota*” is now considered a separate immune organ (maybe up to 75% of immune system);
- ✿ Altered by antibiotics and poor diet

Probiotics

- ✿ Use of probiotics in mice:
improvements or prevention of RA, MS
and type-1 diabetes
- ✿ Improvement seen with **periodontitis**
- ✿ Dietary sources: yogurt, kefir or lassi
with live cultures, aged cheese,
fermented foods (brine-cured, non-
vinegar pickles, sauerkraut, kimchi,
miso)

Probiotics

- ✿ Bacterial supplements should have billions of cultures and include at least Bifidobacterium and lactobacilli (casei, rhamnosus)
- ✿ The “jury is still out” on which strains are best for which condition.
- ✿ Keeping them refrigerated prolongs effectiveness

Probiotics

- ✿ Caution in those with severe immune-compromised states, malignancy, central venous catheters, cardiac valve disease, diabetes, infancy or advanced age
- ✿ Rare fungal infections reported in those taking the probiotic yeast, *Saccharomyces boulardii* (Florastor)

Whey

- ✿ Has been looked into as dietary source of cysteine, needed for glutathione production, an important element in anti-oxidant defense
- ✿ Glutathione itself as an oral supplement is not well-absorbed
- ✿ This may be helpful for autoimmune disease and myopathies but data is very limited, mostly presumed

Whey

- ✿ Typical doses are 20-30 grams daily.
- ✿ Very safe: reports of intestinal discomfort and fatigue with high doses; one case of liver injury in weightlifter also taking creatine supplement.

Other supplements

- ✿ Vitamins C and E: no good data

- ✿ L-carnitine: no good data

- ✿ Glutamine:

- ✿ Because it inhibits muscle wasting and preserves muscle protein, it may help myotonic muscular dystrophy

- ✿ Can raise methotrexate levels; no good data on myositis

Supplements that may do more harm than good

✿ Spirulina (*S. platensis*) and blue-green algae (*Aphanizomenon flos-aquae*)

- ✿ At least two patients with DM had a flare or onset of their disease after taking these

- ✿ Lee A. *Arch Dermatol* 2004;140:723

- ✿ Konno T. *Rinsho Shinkeigaku* 2011;51:330

✿ Echinacea (purple coneflower)

- ✿ Has produced flares of lupus, including kidney-related complications

✿ Alfalfa

- ✿ Has caused lupus-like symptoms in animals
- ✿ Sprouts and tablets have been linked to lupus in humans



There is hope...

Diets and supplements with
some evidence regarding
myositis

Gluten Sensitivity

- ✿ Association of myositis with gluten sensitivity described since at least 1976
- ✿ There have been reports of clinical improvement following a gluten-free diet in **PM, DM and IBM**
- ✿ Not all patients will have positive antibodies (anti-glutaminase/gliadin/endomysial, etc.)

Gluten Sensitivity

✿ Symptoms can range from none to:

- ✿ Weight loss
- ✿ Abdominal cramping
- ✿ Bloating
- ✿ Loose stools
- ✿ Anemia
- ✿ Evidence of bone loss
- ✿ Vitamin E deficiency

Gluten sensitivity: Substitutions

- ✿ Brown rice
- ✿ Quinoa
- ✿ Buckwheat
- ✿ Millet
- ✿ Sorghum
- ✿ Teff
- ✿ Amaranth
- ✿ Tapioca

Many available as:

- ✿ Breads
- ✿ Pasta
- ✿ Cereals
- ✿ Flours

Creatine: Definitions and Clarifications

- ❖ Creatinine: metabolized end-product of creatine, found in blood, muscle and urine; *measured to assess renal function*
- ❖ Creatine kinase (CK) or creatine phosphokinase (CPK): muscle enzyme involved in energy production; *measured to assess skeletal muscle inflammation or damage*, as well as in brain and heart muscle

Supplements: Creatine

- ✿ Taken as a daily *supplement* to improve muscle strength and/or mass
- ✿ A 2011 Cochrane review deemed it a worthwhile supplement with few side effects for those with DM and PM
- ✿ Most data was taken from a 2007 study done in the UK and Sweden (Dr. Ingrid Lundberg was a co-author)
 - ✿ Chung et al. *Arthr Rheum* 2007;57:694-702

Supplements: Creatine

- ✿ Dosage used in the 2007 study:
 - ✿ Start with 20 grams per day for 8 days (loading dose)
 - ✿ Continue with 3 grams per day (maintenance dose)
- ✿ Noted improved performance, ability to undertake high-intensity exercise and endurance work
- ✿ Effect maintained over 5 months

Supplements: Creatine

- ✿ Safety: there were no side effects noted
- ✿ Previous concerns about renal (kidney) toxicity do not seem warranted, as long as there is no underlying renal disease
- ✿ Unfortunately, this does not seem to be effective for inclusion-body myositis (IBM)

Summary

- ✿ Eat a varied diet of mainly fresh plant-based foods, lean (wild, organic?) protein, good fats
- ✿ Avoid salt, bad fats, processed and high-glycemic foods
- ✿ Focus on whole foods rather than supplements
- ✿ Consider probiotics
- ✿ Probably avoid spirulina and blue-green algae, possibly alfalfa, echinacea

Summary

- ✿ For all, but DM especially: check vitamin D level
- ✿ For anyone on MTX: take folic acid
- ✿ For PM, DM, IBM: consider gluten-free trial
- ✿ For PM, DM: consider creatine
- ✿ Stay hopeful for more data on coenzyme Q10, whey and curcumin-piperine, but maybe worth a try

Resources: General

- ✿ Center for Science in the Public Interest
 - ✿ www.cspinet.org
- ✿ American Society for Nutrition
 - ✿ www.nutrition.org
- ✿ Tufts University Healthletter
 - ✿ Healthletter.tufts.edu

Resources: Drug interactions

- ✿ http://drugs.com/drug_interactions
- ✿ <http://reference.medscape.com/drug-interactionchecker>
- ✿ <http://www.healthline.com/druginteraction>

Resources: Supplements

- ✿ **Consumer Labs** (small fee to join)
 - ✿ consumerlab.com
- ✿ **Office of Dietary Supplements**
 - ✿ dietary-supplements.info.nih.gov
- ✿ **Linus Pauling Institute** (Oregon State U.)
 - ✿ <http://lpi.oregonstate.edu/infocenter>
- ✿ **National Center for Complementary and Alternative Medicine (NIH)**
 - ✿ nccam.nih.gov

Resources: Books

- ✿ *Eat to Live* by Joel Fuhrman, MD
(general healthy eating); drfuhrman.com
- ✿ *The Happiness Diet*, by Tyler Graham and Drew Ramsey, MD
- ✿ *Integrative Rheumatology* by Randy Horwitz, M.D. and David Muller, MD
- ✿ *Wheat Belly* by William Davis, MD
(gluten sensitivity);
www.wheatbellyblog.com
- ✿ *The Probiotics Revolution* by Gary Huffnagle, PhD



Any questions?