# Complementary Medical Therapies in Lupus



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The Lupus Encyclopedia
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## How doctors "think" when recommending treatments



- "... group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine"
   National Institutes of Health
- CAM = Complementary and Alternative Medicine

 Nonconventional therapies used along with conventional therapies

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#### Large Categories of CAM

- Mind-Body Medicine
  - Biofeedback, prayer, meditation, relaxation and art therapies
- Biologically Based Practices
  - Dietary supplements, herbal therapies, folk medicine
- Manipulative and Body-Based Practices
  - Chiropractic therapy, massage, colonic irrigation and cleansing
- Energy Therapies
  - Qi gong, Tai chi, Reiki, therapeutic touch, magnetic therapy
- Whole Body Systems
  - Chinese medicine, acupuncture, Ayurveda, witchcraft, homeopathy, naturopathy

#### MIND-BODY MEDICINE:

- Belief = mental and emotional factors influence health and well-being
- Becoming a part of mainstream medicine
- Most commonly used for:
  - Pain
  - Anxiety
  - Panic disorder
  - Insomnia
  - Headaches
  - Depression



- Teach brain to control processes not under conscious control
  - Blood pressure
  - Brain waves
  - Heart rate
  - Muscle tension
  - Temperature



- Teach brain to control processes not under conscious control
  - Blood pressure
  - Brain waves
  - Heart rate
  - Muscle tension
  - Temperature
    - Raynaud's phenomenon



- Do I recommend this?
  - Yes, for:
    - Raynaud's phenomenon
    - Stress
    - Pain
    - Insomnia

## MIND-BODY MEDICINE: Relaxation Therapies

- Large group of techniques
  - Stress reduction
  - Prayer
    - 57% of studies have + results
  - Meditation
    - RA studies show ↓ joint pain and tenderness
  - Hypnosis
    - Studies show ↓ anxiety and cancer pain
    - 2012 fibromyalgia study = ↓ pain/fatigue and ↑ sleep
  - Art Therapy
    - Can help to lessen emotional impact of chronic disease

#### Relaxation Therapies: Stress reduction

- Studies show stress can cause lupus flares
  - Divorce
  - Death of loved one
  - Intermittent normal stress ("daily hassles")
  - Immune system → more active during stress
- 2006 study looked at a stress gene
  - Gene predisposes people to become more stressed than normal
  - Gene makes it more difficult to produce serotonin in brain
    - Serotonin required for mood stabilization and pain relief
  - Lupus patients with this gene had increased lupus nephritis flares when exposed to stress
- Many lupus patients have difficulty with memory
  - Cognitive dysfunction
  - Associated with increased stress

- Learn to say "no"
- Ask for help
- Proactively lighten your load
- Prioritize things in life
- Yoga and T'ai chi
- Biofeedback to learn to decrease anxiety and stress
- Learn deep breathing exercises and "mental imagery"
- Prepare well ahead of any major activity
- Learn to practice good time management
- Schedule rest and relaxation time EVERY DAY

- Say positive things to yourself daily; Complement yourself
  - Don't say negative things; don't criticize
- Plan on arriving early for all appointments and events
  - Get ready/prepare for all events earlier than you think is needed

- Learn not to argue with others
  - Learn to accept that everyone has differing ways of doing things
  - Many conflicts are not important in the scheme of life
  - Learn to relax, take a deep breath, leave before an argument occurs
  - Leave before you say something you may regret

- Learn to live at or below your means
  - Too much stress is caused by money problems
  - Don't try to keep up with the "Joneses", friends, and other family members
  - Studies show that happiness is not increased by material things
  - Ask "is this something I truly need?" OR "is it just something I want?"

- Exercise regularly
- Schedule in at least 8 hours of sleep a night
- Do not skip healthy, planned meals
- Avoid unhealthy meals (sweets, carbs, greasy foods, "fast food")
- Learn better communications skills if you have difficulties with relationships
- Pray, meditate, hypnosis, art therapy

#### **BIOLOGIC-BASED PRACTICES:**

- Dietary supplements
- Herbal therapies
- Folk medicines

# Dietary Supplements: Supplements Possibly Helpful in Some People with SLE

- DHEA
- Omega-3 fatty acids
  - Fish oil
  - Flax seed oil
  - Walnuts
- Vitamin D

- DHEA = DeHydroEpiAndrosterone
  - A steroid hormone
  - Produced by adrenal glands
  - Converted in body to male sex hormones



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  - A steroid hormone
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- Lower levels than normal in SLE
- Taking DHEA in studies:
  - Decreases # of lupus flares
  - May help decrease mild lupus symptoms
  - May help decrease doses of steroids
  - Increases bone density

#### Potential side effects:

- Acne (55%)
- Increased hair growth (15%)
- Decreases in HDL (good cholesterol)
- Elevated liver enzymes
- Elevated blood pressure

#### Do not take if:

- You have significant liver disease
- Polycystic ovarian syndrome
- Without checking with your doctor 1st

- Dosage used in studies:
  - 200 mg a day
- Best obtained by prescription:
  - Compounding pharmacist
    - Village Green Apothecary, Bethesda MD
    - ComCare Pharmacy, Bowie MD

- Have beneficial effects on cholesterol and inflammation
- American diets relatively deficient in these fats
  - Higher in omega-6 fatty acids from non-fish meats
  - Omega-6 fatty acids increase cholesterol and inflammation



- Omega-3 fatty acids abundant in:
  - Flax seed (highest concentration found)
  - Walnuts
  - Tofu
  - Shrimp
  - Scallops
  - Cold water fish
    - Salmon
    - Halibut
    - Snapper
    - Mackerel
    - Albacore
    - Sardines



- Lupus mice fed diet high in omega-3 fatty acids:
  - Less immune system activity
  - Lower autoantibody production
    - Anti-ds DNA
    - Antiphospholipid antibodies
  - Less lupus kidney inflammation (nephritis)
  - Less kidney damage



- Human study: 12 patients
  - 5 weeks, 6 grams fish oil daily
  - Followed by 5 weeks "normal diet"
  - Followed by 5 weeks 18 grams fish oil a day
  - Cholesterol levels improved on higher dose of fish oil
  - No differences in their lupus
- Another human study: 26 patients with lupus nephritis
  - 2 years
    - Part time on high doses of fish oil
    - Part time on "normal diet"
  - Cholesterol improved
  - Lupus kidney disease did not improve

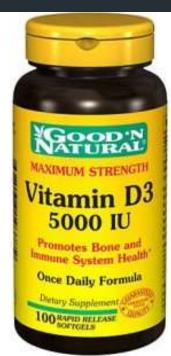
- Human study: 27 patients
  - Diet high in fish oils
  - Decreased lupus activity compared to placebo
  - Improved blood work compared to placebo
- Another study: 22 pregnant women with antiphospholipid antibody syndrome with recurrent miscarriages
  - Took omega-3 fatty acid supplements daily
  - Only one premature fetal death (lower than expected)

- Sjogren's syndrome
  - Several studies
  - Omega-3 fatty acids improve eye tear production

- Summary of studies:
  - Cholesterol values improved in all studies
  - Mice studies encouraging for improving lupus activity
  - Human studies mixed results
    - Only study with positive results used diet, not supplements
  - Questions:
    - Possibly better to do studies in milder lupus?
    - Which is better? Supplements vs diet?
  - Need larger, better human studies in lupus
  - May improve tear production in Sjogren's syndrome

#### Dietary Supplements: Vitamin D

- Most lupus patients have low vitamin D levels
- Vitamin D is essential for proper immune system function
- More severe SLE associated with lower vitamin D levels



### Dietary Supplements: Vitamin D

- Have your levels checked by your doctor
  - Take a supplement if low
  - Eat vitamin D rich foods:
    - Cod liver oil
    - Salmon
    - Mackerel
    - Tuna fish
    - Vitamin D fortified milk and orange juice
  - Vitamin D level goal?
    - Johns Hopkins study suggests a level of around 40 mg/dL

### Dietary Supplements: Controversies

#### Melatonin

- Released by pineal gland in when less light
  - Signals brain to prepare to sleep
  - Used as a sleep aid
  - Used when traveling across many time zones
  - May increase immune system activity
- 2 lupus mouse studies
  - Female mice lupus improved
  - Male mice lupus worsened
- No human lupus study
- 1 rheumatoid arthritis human study
  - Melatonin → no difference in disease activity
- My recommendation based on this:
  - Melatonin used for sleep may be safe in women with lupus
  - Men with lupus should avoid melatonin



### Dietary Supplements: Controversies

#### Garlic

- Some lupus sources recommend not eating garlic or taking garlic supplements
- I can find no studies in lupus to back this recommendation
- Some naturopaths advocate using garlic to "decrease inflammation"
- My recommendation
  - Eat garlic!



#### Lupus Diet:

- Avoid alfalfa and mung bean sprouts
- Lower than average calorie diet
- Low fat
- Olive oil
- Alcohol in moderation?
- Rich in omega-3 fatty acids
  - Flaxseed
  - Cold water fish
  - Walnuts
- Vitamin D rich foods

### Lupus Diet: Avoid mung bean and alfalfa sprouts

- Contain amino acid L-canavanine
- Stimulates the immune system → more active
- 2 studies in monkeys:
  - Fed ground alfalfa sprouts
  - 3 of 5 macaque monkeys developed lupus symptoms
    - Lupus nephritis
    - Hemolytic anemia
  - Developed abnormal lupus blood results
    - + ANA, +DNA, low complement levels
- Baltimore Lupus Environmental Study
  - Eating alfalfa sprouts →
  - Increased chance of lupus



#### Lupus Diet: Less calories than average Low fat diet

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- Mice with lupus fed low calorie diet
  - Live longer
  - Less lupus kidney disease
  - Less salivary gland inflammation (Sjogren's syndrome)
- Lupus mice fed high fat diet
  - Increased immune system activity
  - Increased autoantibody formation



#### Lupus Diet: Olive Oil

- Rich in eicosapentaenoic acid (a type of omega-3 fatty acid)
- One study, 27 patients
  - 20 grams olive oil daily (close to 1 ½ tablespoons)
  - Lupus activity improved over 34 weeks
  - 17 patients completed study
  - Lupus activity improved



### Lupus Diet: Alcohol in moderation?

- Several studies show that moderate intakes of alcohol
  - Lower risk for lupus in some studies
  - No increased risk for lupus in others
- Many studies show that moderate intake of alcohol →
  - Decreased cardiovascular problems (#1 cause of death in lupus)
  - Increases good cholesterol levels (HDL)
  - May decrease certain cancers



### Lupus Diet: Alcohol in moderation?

- Definition of "moderate" alcohol allowable per 24 hours
  - Women = no more than
    - 5 oz wine daily
    - 12 oz beer
    - ½ ounce liquor
  - Men = no more than
    - 10 oz wine daily
    - 24 oz beer
    - 1 oz liquor



### Lupus Diet: Alcohol in moderation?

#### Cautions!

- May ↑ risk of breast cancer in genetically predisposed women
- Do not drink if you have had a substance abuse problem
- Do not drink if alcoholism runs in your family
- Should restrict alcohol amounts with certain medications
  - NSAIDs → increased risk of ulcers
  - Tylenol → liver problems if you drink too much alcohol
  - Narcotics and pain relievers → too drowsy
  - Methotrexate → liver problems
  - TALK TO YOUR DOCTOR 1st



#### Twhf

- Chinese herb
- Has anti-inflammatory properties
- 5 small studies in total of 249 lupus patients
- Showed improvements in some lupus symptoms
  - Fatigue
  - Joint pains
  - Fever
  - Rash
  - Lupus nephritis
  - Improved platelet counts
- Side effects:
  - Diarrhea, nausea, vomiting, hair loss, mouth sores, high blood pressure, infertility, fetal malformations
  - One death (man died from heart toxicity)

Do I recommend this?



- Do I recommend this?
  - NO!



- Do I recommend this?
  - NO!
- However, it should be studied further, purified, and the benefits and potential side effects defined better

## Herbal Therapies: Echinacea

- From the cone flower (Echinacea purpurea)
- Used to treat colds and flu
  - Though refuted in larger medical studies
- Increases immune system activity
- Can worsen lupus
  - Series of lupus patients at Johns Hopkins Hospital got worse while taking Echinacea
  - 2 patients required strong chemotherapy for lupus nephritis

# Herbal Therapies: Echinacea

Never take Echinacea



#### Folk medicine biological therapies:

- Vary from culture to culture
  - Botanicas = Stores common in Latin cultures
- Rattlesnake capsules
  - Reports of lupus patients getting Salmonella poisoning
  - Reports of deaths in other patients



#### Manipulative and Body-Based:

- Chiropractic therapy
  - No lupus studies
  - Lupus does not affect joints of the spine
- Massage therapy
  - May help ↓ stress and muscle spasm pain
- Colonic irrigation and cleansing



### Manipulative and Body-Based: Colonic irrigation and cleansing

- Belief: "toxins" in colon are unhealthy and cause disease
- Fluids are used to clean out the colon
- There are NO studies for ANY disease to show benefit



# Manipulative and Body-Based: Colonic irrigation and cleansing

- Potential dangers in lupus
  - Dehydration
  - Bowel perforation
  - Increased risk of infection
- Do I recommend this?

# Manipulative and Body-Based: Colonic irrigation and cleansing

- Potential dangers in lupus
  - Dehydration
  - Bowel perforation
  - Increased risk of infection
- Do I recommend this?
  - NO!

#### ENERGY THERAPIES

- Attempt to manipulate energy fields in and around the body
  - Qi gong
    - Studies show ↓ arthritis and neck pain
  - T'ai chi
    - Studies show ↓ pain from fibromyalgia and osteoarthritis
  - Reiki
    - 2011 Cancer study = ↓ pain/anxiety, ↑ sleep
  - Therapeutic touch
    - Studies show ↓ pain and anxiety
  - Magnetic therapy



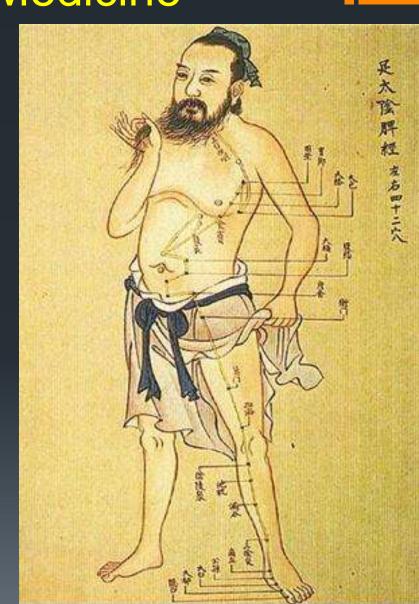
# ENERGY THERAPIES: Magnetic therapy

Help with pain 30 - 35% of the time



### WHOLE BODY SYSTEMS: Traditional Chinese Medicine

Thousands of years old



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- Thousands of years old
- Theory: Improper flows of energy through the body → disease
  - Opposing forces of yin and yang
  - Proper balance is essential



#### WHOLE BODY SYSTEMS: Traditional Chinese Medicine

- Thousands of years old
- Theory: Improper flows of energy through the body → disease
  - Opposing forces of yin and yang
  - Proper balance is essential
- Combines:
  - Diet
  - Chinese herbs
  - Massage
  - Meditation
  - Acupuncture
  - Tai chi



- Lupus nephritis = deficiency of kidney yin or liver-kidney yin
- At least 8 studies performed in lupus nephritis
  - Better results when used in combination with conventional medicines
  - Fewer side effects in the Chinese herb + conventional medicine groups
  - Vast majority of studies = in Chinese medical journals
  - No large, well done studies done in Western journals

- Potential downsides
  - Herbs do have medicinal effects on the body
    - Side effects reported =
      - Severe kidney disease
      - Anemia
      - Heart problems
  - No agency regulates quality
  - A Chinese study studied 430 samples
    - From Taiwan hospitals, medical centers and herb stands
    - 1/3 adulterated with Western medicines

Do I recommend using Chinese herbs?

- Do I recommend using Chinese herbs?
  - NO!

- Summary
  - Need larger, better studies critically assessed internationally by lupus experts
  - If found to be helpful and safe, need to be regulated to ensure high quality products

- Affects the flow of energy (qi)
- Restores balance of yin and yang
- Some studies show benefits for pain and arthritis



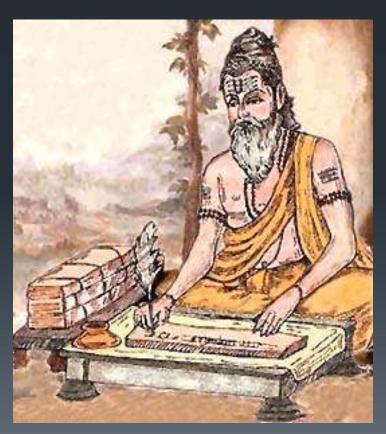
- Lupus studies
  - 2008 study for fatigue and pain showed no benefit
    - Study was small
  - Chinese study showed benefit for discoid lupus
    - Only 15 patients
    - No placebo group
- Rheumatoid arthritis studies
  - The best study = no benefit

What is my recommendation?

- What is my recommendation?
  - "Depends"
    - Lack of proven benefit vs expense makes it hard to recommend
    - However, it is safe, and some arthritis studies suggest benefits to decrease pain

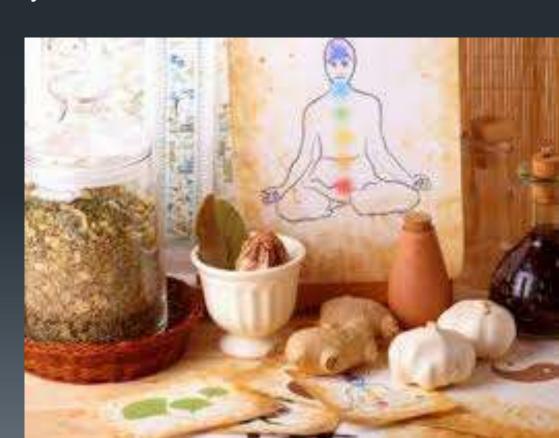
# WHOLE BODY SYSTEMS: Ayurveda

- India
- Thousands of years older
  - Older than traditional Chinese medicine
- Belief = Imbalance of body's life forces → illness



# WHOLE BODY SYSTEMS: Ayurveda

- India
- Thousands of years older
  - Older than traditional Chinese medicine
- Belief = Imbalance of body's life forces → illness
- Combination of:
  - Diet
  - Herbs
  - Massage
  - Meditation
  - Yoga
  - Fasting
  - Internal cleansing



#### Ayurveda: Yoga

- A Hindu healing system
- Many different forms
- Includes:
  - Breathing control
  - Simple meditation
  - Holding body in specific postures



# Ayurveda: Yoga

- No lupus studies
- Beneficial studies in fibromyalgia
  - Especially "Yoga of Awareness" or "Kundalini yoga"
  - Decreased pain
  - Improved mood
  - Decreased fatigue



#### Ayurveda: Yoga

Do I recommend this?

#### Ayurveda: Yoga

- Do I recommend this?
  - YES
  - Especially for lupus patients who also have fibromyalgia
    - "Yoga of Awareness" or "Kundalini yoga"



Use of magical and supernatural powers



- One case of severe lupus nephritis
  - Filipino witch doctor
  - Removed a curse put on her by previous boyfriend
  - "Cured" a few weeks later

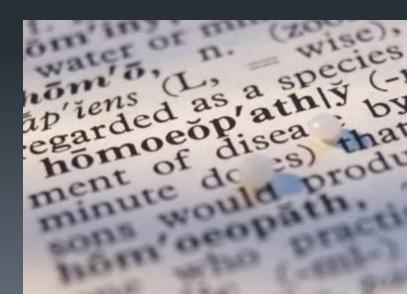


Do I recommend this?



- Do I recommend this?
  - No!

- Homeo
  - Greek for like
- -opathy
  - Greek for disease
- "Like cures like"
  - If something causes problems or a disease when given in large doses
  - It may cure the disease when given in tiny doses



- No lupus studies
- 6 studies in fibromyalgia
  - All the studies had major study design flaws
  - Therefore, no proof of benefit



Do I recommend this?

- Do I recommend this?
  - NO

# WHOLE BODY SYSTEMS: Naturopathy

 Emphasizes prevention and treatment of disease through healthy lifestyle



### WHOLE BODY SYSTEMS: Naturopathy

- Emphasizes prevention and treatment of disease through healthy lifestyle
- Combines:
  - Herbs
  - Homeopathy
  - Physical Therapy
  - Mind body therapy
  - Exercise
  - Diet
  - Stress reduction



# WHOLE BODY SYSTEMS: Naturopathy

- How to choose a naturopathic (or integrative medicine) doctor
  - Graduated with a degree from a recognized institution
    - N.D. (doctor of naturopathy)
    - N.M.D. (doctor of naturopathic medicine)
  - Currently licensed by the ruling state or national agency
  - Carries malpractice insurance
  - Member in good standing with a professional organization for naturopathic doctors
  - The office and doctor's manners are professional
  - Doctor provides diagnoses, treatments and has reasonable expectations of results of treatment
  - Keeps accurate records
  - Willing to send notes to your other doctors

#### Never take in lupus summary

- Mung bean and alfalfa sprouts
- Melatonin (if male)
- Any herbal supplements
  - Echinacea
  - Anything that "boosts" or "supports" the immune system
- Folk medicine pills
- Colonic cleansings

#### :Probably helpful in lupus summary

- Biofeedback
  - Especially for Raynaud's
- Stress reduction techniques (page 4)
- DHEA
- Vitamin D supplements

#### Possibly helpful in lupus summary

- Prayer, meditation, hypnosis
- Omega-3 fatty acid foods
  - Fish, flax seed, walnuts
- Olive oil in diet
- Low fat, low calorie diet
- Vitamin D rich foods
- Alcohol in moderation
- Massage
- Qigong, Tai chi, Reiki, therapeutic touch
- Acupuncture
- Yoga

#### Probably not helpful, but safe

- Chiropractic therapy
- Magnetic therapy
- Witchcraft
- Homeopathy

#### Help Us Solve The Cruel Mystery

FOUNDATION OF AMERICA DC/MD/VA CHAPTER