National Jewish Health®

Complementary and Alternative Medicine in ALS

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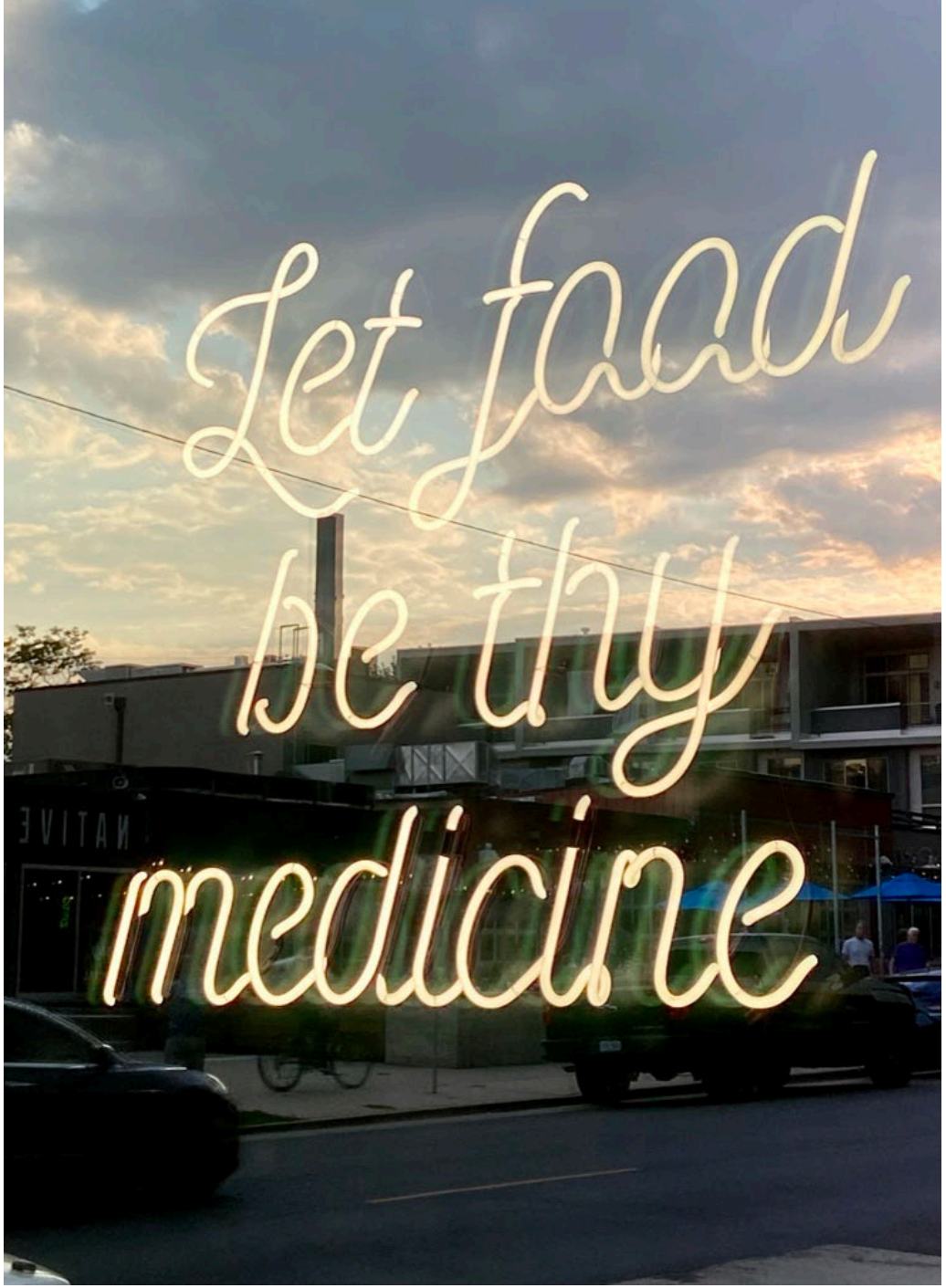
Complementary and Alternative Medicine in Neurology

1. Nutrition
   - Food as medicine
2. Exercise
   - Healthy body, healthy brain
3. Supplements – EVIDENCE BASED
4. Mind-body therapies
   - Yoga, meditation, tai chi


Let food
be thy
medicine

Nutrition for ALS patients: what's the evidence?

- Energy balance
- Higher BMIs 30 to 35kg/m2 correlate with:
  - Reduced risk of disease
  - Later disease onset
  - Longer survival time
- Increased fat mass on MRI predictor of survival among men
- Lower BMIs/rapid weight loss negative effect
  - 7.7 fold increase in mortality in malnourished ALS pts

Nutrition – Specific diets

- High calorie diet (up to 20% more than usual)
  - Clinical trial to restore weight in 24 patients
  - High carb vs high fat
  - Both effective after 12 weeks
  - Animal trial: survival benefit in mice with ALS
- Ketogenic diet with mixed results
  - Not currently recommended
- Gluten free diet
  - May be helpful for weight loss, autoimmune conditions (no data for ALS patients)

Nutrition – Specific diets

Clinical trial of 3 diets, n=24 people

1. Regular diet: Jevity 1.0; 29% fat calories
2. Hypercarbohydrate hypercaloric diet:
   Jevity 1.5; 29% fat calories
   - Reduced deaths compared to controls, hyperfat diet
3. Hyperfat hypercaloric diet: Oxepa; 55% fat calories with eicosapentaenoic acid and gamma linoleic acid

Nutrition - specific diets:

- Omega 3 fatty acids: **worsened disease** in mice when given at onset or during the disease
- Deanna Protocol (DP)– "winning the fight"
  - List of supplements that can be ordered online
  - Costs $400/month although recently ↓ $159.99
  - **Limited data with flawed methodology**: only one published animal study
  - Cell model study: Stem cell-derived motor neurons from familial and sporadic ALS that were treated with glutamate showed reduced stress with DP

Nutrition

- Healthy carbohydrates
  - Quinoa, oats, beets, bananas, oranges, sweet potatoes
- Protein:
  - Fish
  - Chicken
  - Lean cuts of red meat
  - Beans, lentils, chickpeas

Nutrition – Fruits and vegetables

Fruits and vegetables - 5 servings/day

Choose brightly colored fruits and veggies, e.g., tomatoes, berries, broccoli, avocado, and spinach

Berries= brain food

May function as a natural "aricept"

Has catechins

Nutrition: Catechins

- Antioxidant found in plants, fruits, vegetables
- Green tea, blueberries, cocoa, prune juice, ginko biloba
- Animal studies
  - reduced motor neuron hyperexcitability
  - delayed onset of disease
  - extend life span

Nutrition: Chocolate and Nuts

- Dark Chocolate
  - Contains theobromine, assoc with 7-9hrs sleep
  - Flavanols: increases cerebral blood flow
  - Assoc w reduced risk of dementia
  - AVOID EATING BEFORE BEDTIME
- Nuts
  - Brazil nuts (selenium), cashews (Cu, Mg), almonds (Ca, Vit E), pistachios (lutein, B6), walnuts (Om 3FA)

Nutrition and Cramps

- Balanced diet
  - Foods rich in K, Ca, Mg
  - Avocado, sweet potatoes, beans, bananas, melons
- Hydration
  - Esp with diuretics, heat exposure or exercise
- Frequent small meals
- Pre-exercise carb loading
- Avoidance of fasting

Nutrition and Cramps

- Pickle juice
  - Inhibits electrically induced cramps in 85s
  - Acetic acid may trigger oropharyngeal reflex inhibiting alpha motor neurons
  - Not related to salt/electrolyte replacement
- Watermelon
  - Contains L-Arginine
- Sports drinks
  - Slightly better than H20

Exercise

4 Rules of Exercise

- 1. Pick something you like or can tolerate
- 2. If you feel tired or worse 2 hours after you've worked out you've done too much
- 3. Try to do something every day
- 4. No Pain/No Gain does not apply

Exercise

- Stretching
- Graded exercise
- Aim for 150min/week
- Aqua therapy
- Recumbent bicycle
- Massage

Supplements

Supplements

- Acetyl L carnitine: 3gm three times daily
  - may slow decline and increase survival
- Vitamin E: no effect on survival but may delay onset in mice
- Vitamin D: lower levels (<25nmol/L) with increased risk of death
  - 2000IU/D safe and may be beneficial
- Resveratrol: polyphenol found in skin of grapes and berries
  - improves survival in mice with ALS

Supplements

- Curcumin: may slow progression, reduce oxidative stress.
  - Doses vary
  - Difficult to digest
- Melatonin: mixed data, may exacerbate neurodegeneration
- *AVOID Vitamin A: reduced survival in mice*
- *AVOID Omega-3 fatty acids: worsening spinal cord changes in animal studies*

Supplements: Ultra-high B12 dose

- PHASE II/III STUDY 2019: no difference between methylcobalamin (25 or 50mg twice weekly for 3.5 years) and placebo but early ALS pts with slower progression
- PHASE III STUDY 2022 (JETALS study):
- 130 patients with early stage ALS
- None with invasive or non-invasive vent support
- Methylcobalamin 50mg twice weekly injection for 16 weeks
- Reduced functional decline by 43% on ALSFRS

Supplements: Chinese herbs

- Huolingshengji (HLSJ)
  - Prolonged survival and reduced motor neuron loss in animal studies 
  - Slowed progression in human studies
- Dihuang Yinzi
  - Improved muscle strength in one patient only 
- Jiawaei Sijunzi (JWSJZ)
  - Possibly slower decline in ALS FRS 
- Jaeumganghwa-Tang (JGT)
- Gamisoyo-San (GSS)

Supplements

- No data or no change:
  - Thiamine – no data
  - Riboflavin – no change in animals
  - Vitamin C – no change in 5 studies
  - CoQ10 – no change with 3000mg
  - Ibedenone – mixed results, pulled from market in 2013; still available OTC
  - Creatine - no change with 5-10mg

Medical Marijuana in ALS

- CBD1 and CBD2 receptors throughout CNS and PNS
- Endocannabinoid system may be part of the pathophysiology of ALS
- CBD non psychoactive component with anti-inflammatory and antioxidant properties
- CBD may slow disease progression in ALS
- Helps with symptoms of pain, saliva management, spasticity, loss of appetite, depression

Medical marijuana

- Adverse psychologic and cognitive effects: memory loss, suicide, mood disorders, psychosis, lower IQ and decline in school performance in children
- Diversion
- Not federally regulated

Nugent et al Ann Int Med 2017;167:319-331


MEDITATION,
BECAUSE SOME QUESTIONS
CAN'T BE ANSWERED BY GOOGLE.

Mind-body therapies

- Meditation
- Mindfulness based stress reduction (MBSR)
  - Sitting meditation, yoga, breathing exercises
- Qigong
- Tai chi
- Restorative yoga
- Acupuncture

Mind-body practices

Acupuncture

- Helps with pain control
- Very small (possibly insignificant) improvements in oxygen saturation (95.42 % vs 95.58%)
- Possible improvements in motor function in combination with Chinese herbs (flawed methodology)

Yoga

- Restorative yoga for patients with limited ambulation
- May help with cramps

Basic Methods of Meditation

- Concentration
  - Focus on breathing either under the nose or at the chest/abdomen
  - FOCUS ➔ ACKNOWLEDGE ➔ DISENGAGE ➔ RETURN TO FOCUS
  - 6 Step walking method
    - Step 1 – Lift heel
    - Step 2 – Lift toe
    - Step 3 – Move the foot forward in the air
    - Step 4 – Lower the foot Step 5 – Heel down
    - Step 6 – Toe down

Everyday Mindfulness

- Benefits may be seen with just 20 min/D
- Sitting practice with breathing techniques
- Mindful eating
- Mindfulness in the car: 5 deep breaths
- Mindfulness with walking
- Mindfulness at your desk
  - Look out the window or at the ceiling
  - Shift in the gaze=shift in your thoughts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Home based TeleYoga Breathing Meditation in ALS

- 8 week, 1 hour online sessions using zoom videoconferencing
- Primary outcome: lung measurements (FVC)
- Secondary outcome – quality of life, feelings of shortness of breath
- 10 participants enrolled
  - 4 excluded (1 clinical trial, 1 ventilated, 1 surgery, 1 dropped out)
  - 6 completed the study

Participants in Yoga Breathing Trial

ID#	Age	Sex	Onset	ALS-FRS	BiPAP use
1	55	F	Limb	36	No
2	60	F	Limb	42	Yes
3	54	M	Limb	40	Yes
4	56	F	Limb	28	Yes
5	41	F	Limb	28	No
6	75	F	Limb	34	No


Zoom Meeting ID: 316-850-866
Gallery View
Yoga ALS1
Angela Nicolosi
Pia Sanpitak
Cancel the Spotlight Video
Recording...
Click if you want to switch to a different microphone or speaker
Mute
Stop Video
Invite
Manage Participants
4
Share
Chat
Pause/Stop Recording
Breakout Rooms
End Meeting

FIGURE 1: Upright FVC(L) Over Time for Participants in Active Intervention