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Integrative Holistic Therapies for ALS

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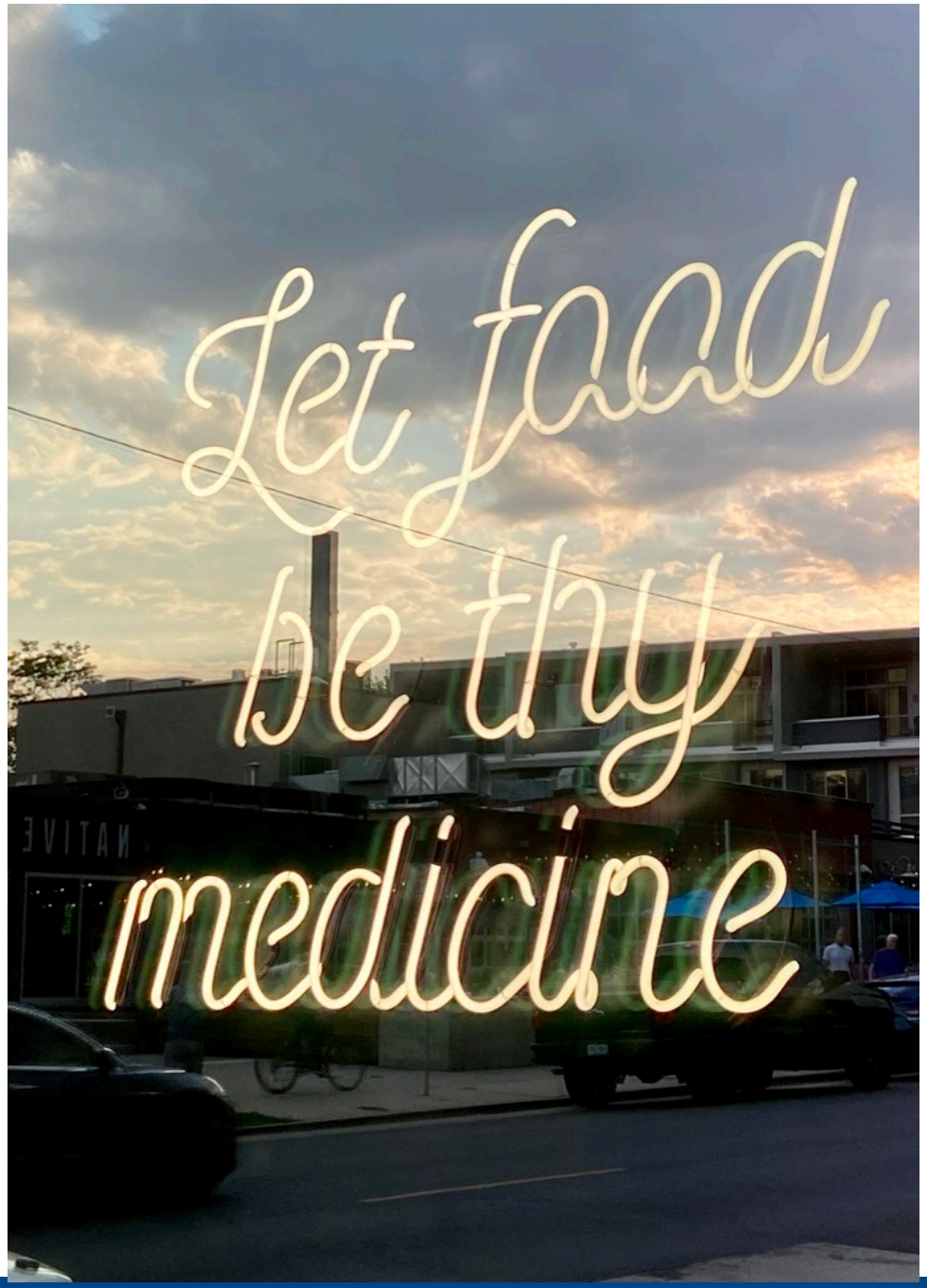
Nutrition


Let food
be thy
medicine

Nutrition for ALS patients: what's the evidence?

- Energy balance
- Higher BMIs 30 to 35kg/m2 correlates 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

Bedlack etal. Clin Neurol 2015;33:909-36

Nutrition – Specific diets

- High calorie diet (20% more than usual)
  - Hypercarbohydrate/hypercaloremic diet
  - Survival benefit in mice, but no benefit in pts with ALS
- Ketogenic diet with mixed results
  - Be careful of weight loss

Nutrition – Specific diets

- Omega 3 fatty acids – (flaxseeds, chia)
  - Higher levels ALA associated with slower decline and 50% lower risk of death
  - Reduced risk of developing ALS
  - **Worsened disease** in mice when given at onset or during the disease
- Gluten free diet
  - Gluten autoimmunity potential ALS trigger
  - Limited data for ALS patients but no increased risk of ALS in celiac patients
  - Be careful of weight loss!

Bjornevik etal Neuroloogy 2023
Yip etal Plos one 2013
Ludviggson et al Eur J Neurol2013

Nutrition - specific diets:

High fat diet (Oxepa; 55% fat calories)

- **Increased adverse events and deaths**

Wahls diet (similar to Paleo):

- **May cause weight loss (7.2% BMI loss in MS pts)**

Deanna Protocol – "winning the fight"

- List of supplements that can be ordered online
- Costs $400/month
- **Limited data with flawed methodology**

Nutrition

- Healthy carbohydrates
  - Quinoa, oats, beets, bananas, oranges, sweet potatoes, brown rice
- 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"

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
  - Especially with diuretics, heat exposure or exercise
- Frequent small meals
- Pre-exercise carb loading
- Avoidance of fasting
- Pickle juice, vinegar

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

Sleep

Sleep

- Patients ≥ 65 years with <5hrs of sleep/night twice as likely to develop dementia compared to those with 6 to 8hrs/night
- Also with increased risk of death
- ≤ 6 hrs/night at age 50, 60, 70 yrs associated with 30% increase risk of dementia compared to 7 hrs
- **Healthy sleep duration= 7 hours**

Sleep hygiene

- Reduce screen time (blue light effect) at least one hr before bedtime (10-3-2-1 rule)
- Reduce alcohol
- Use dimmer lights near bedtime and reduce overhead lighting
- **Sleep regularity**
  - Consistent # of hours more important than actual number
  - Reduces risk of premature death by 20-48%*
  - Irregular sleep: inconsistent sleep/wake times, interrupted sleep and napping

* Windred DP et al. Sleep

Sleep

- **Yoga**: improved sleep latency, total sleep and quality
- **Acupressure/acupuncture**: mixed results with similar benefit in sleep quality to medications
- **Tai Chi**: improved sleep duration, latency, quality and efficiency
- **Mindfulness based stress reduction**
  - Improved total wake time, pre-sleep arousal scale, and insomnia severity
- **Melatonin** 1-5mg taken 30 min to 2hrs prior to bedtime
- **Tart cherries** (contains melatonin)

Sarris etal Sleep Med Rev 2011;15:99-106
Irwin MR etal. Sleep 2008;31:1001-8
Li F etal. J Am Ger Soc 2004;52:892-900
Manjunath NK etal. Indian J Med Res 2005;121:683-90

Supplements

Supplements

- Ashwagandha (withania somnifera)
  - Improved motor function and preserved motor neurons in mice
  - Dose: 1088mg daily and 544mg daily in clinical trial
- Acetyl L carnitine: 1gm 3x/D
  - may slow decline and increase survival
- Vitamin E: no effect on survival but may delay onset in mice and reduce risk

Supplements

- Curcumin: may slow progression
- Melatonin: mixed data, may worsen neurodegeneration
- Vitamin D: lower levels (<25nmol/L) with increased risk of death
  - Dose:1000-2000 IU/D
- Resveratrol: polyphenol found in skin of grapes and berries
  - improves survival in mice with ALS

Supplements

- No data or no change:
  - Thiamine
  - Riboflavin
  - Vitamin C
  - CoQ10
  - Ibedenone
  - Creatine
  - Lion's mane
- Caffeine: conflicting reports
  - worsened some mice
  - no change in human studies
  - can reduce clearance of rilutek
- AVOID Vitamin A: reduced survival in mice

Supplements: Megadoses of B12

- 130 patients with early stage ALS
  - None with invasive or non-invasive vent support
- Methylcobalamin 50mg twice weekly injection for 16 weeks
- May delay functional decline

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 effects:
  - Memory loss
  - Suicide
  - Cognitive impairment
  - Mood disorders, e.g. anxiety
  - Psychosis
  - Paranoia
- Diversion
- Not federally regulated

Andreae et al J Pain 2015;16:616-27.
Nugent et al Ann Int Med 2017;167:319-331

Mind body therapies

Mind-body practices

- Acupuncture
  - May help with pain control, difficulty swallowing, muscle wasting and excess saliva
  - 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
  - May help with cramps

Mindfulness: nonjudgmental awareness of the present moment

Basic techniques

- Focus on breathing either under the nose or at the chest/abdomen
- FOCUS ➔ ACKNOWLEDGE ➔ DISENGAGE ➔ RETURN TO FOCUS
- Walking meditation

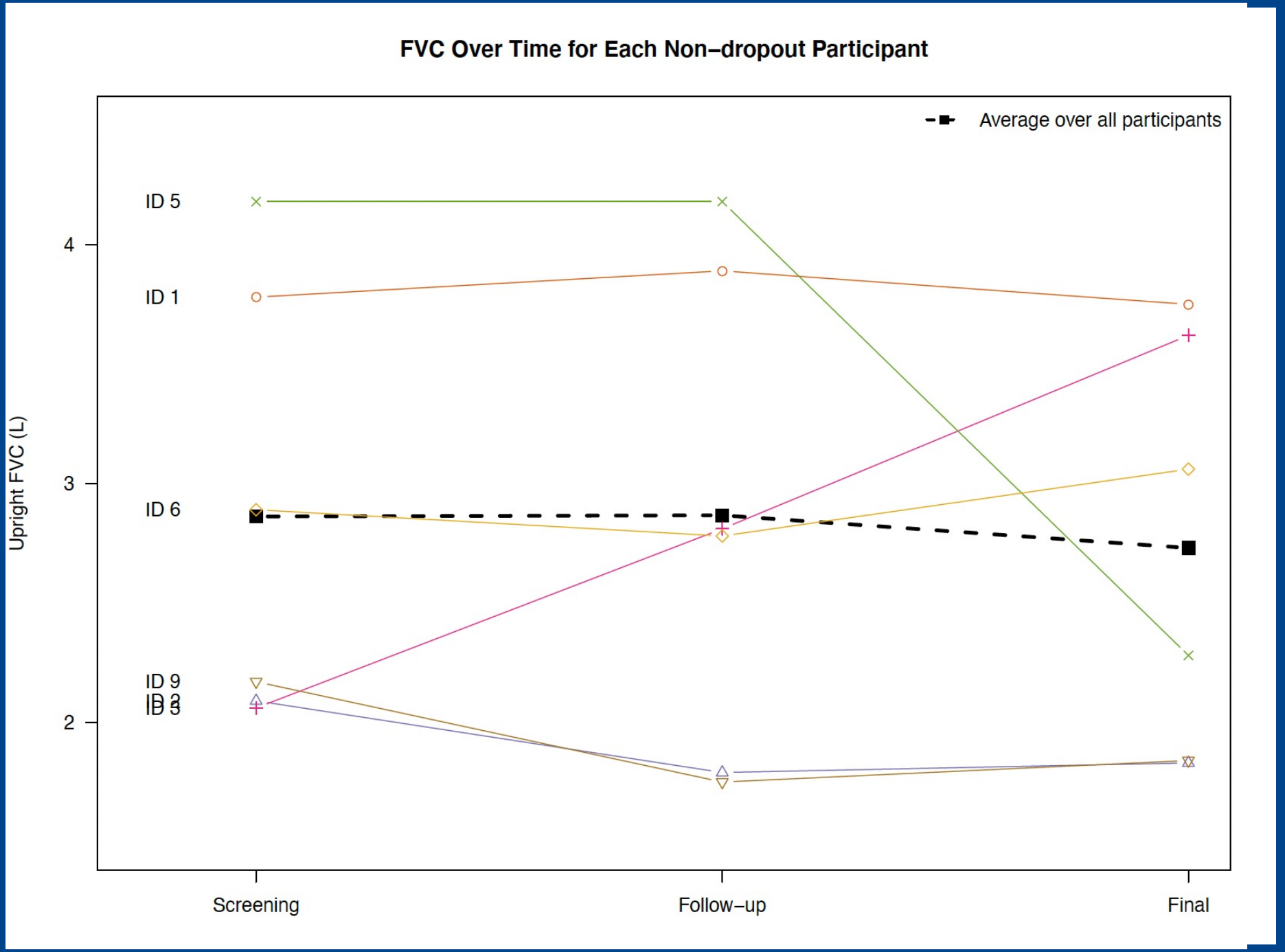
Everyday Mindfulness

- 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


POLARIS

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


FVC Over Time for Each Non−dropout Participant
Average over all participants
ID 5
ID 1
ID 6
ID 9
ID 3
4
3
2
Upright FVC (L)
Screening
Follow−up
Final

Gratitude

Gratitude

- Happiness is when you're grateful for what you have now
- Antidote for desire and jealousy
- Humility
- Connection
- Gratitude exercises

Gratitude

If the only prayer you said was “thank you” it would be enough.

-Meister Eckhardt

Acceptance

Acceptance

- It is what it is
- Cow in the ditch
- Use all the tools you have: mind-body therapies, exercise, relationships, gratitude, patience
- Letting go: time and understanding

The Trail Always Changes

- Keep going
- The ALS community will fight with you and when you're tired, we will fight for you
- Things that will improve quality of life
  - Noninvasive ventilation
  - ALS multidisciplinary care centers