



Quality of Life in MS

Achieving QOL through a Multidisciplinary Approach

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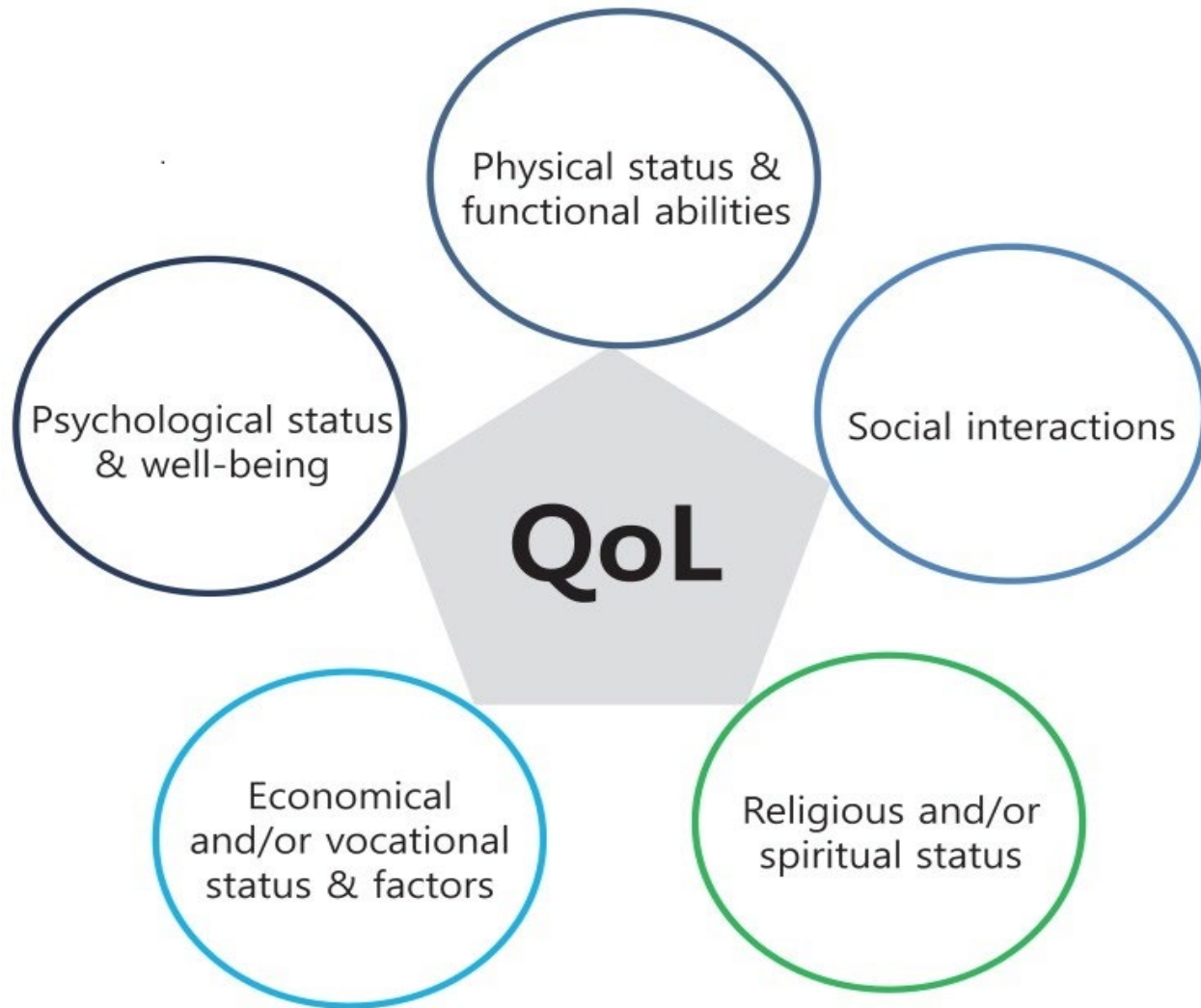


Quality of Life



- What is Quality of Life (QOL)?
- Defined by the World Health Organization as an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns
- Defined by Britannica as the **degree to which an individual is healthy, comfortable and able to participate in or enjoy life events**
- Defined by CDC as an individual's or a group's perceived physical and mental health over time. (HRQOL)

Domains of Quality of Life



Ohio State University leading shared efforts to Achieve QOL

- Identify Goals- Patient and Provider
- Identify areas of deficit in specific domains- Screening tools, diagnostic testing such as EDSS scoring, Fatigue scales, BMI and lab testing
- Formulate a plan of integrated, co-directed intervention – Referrals as needed such as Physical Therapy, Cognitive testing, Dietician, Urology, Ophthalmology
- Define tools to measure success- Follow up intervals, sequential screenings such as every 3-6 months
- Reflect, Refine, Repeat



What to expect in a Quality of life Visit

In the quality of life clinic you will meet with Kristi Epstein, a nurse practitioner with specialty training in MS.

She will talk to you about all the symptoms you have been experiencing related to MS, and how they impact your life.

Survey tools specific to these symptoms will be filled out and evaluated . Based on your answers, a comprehensive management plan will be formulated, and referrals will be made to experts in our MS multidisciplinary management clinic or other OSU clinics to address your symptoms.

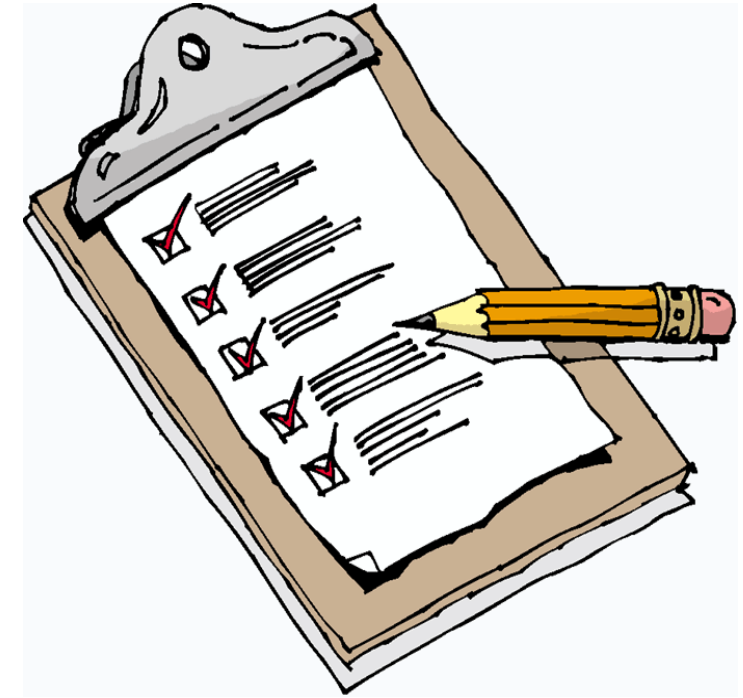
Our experts include a pharmacist, physical therapists, occupational therapists, speech therapists, sleep medicine / fatigue physicians, psychologists, neuropsychologists, urologists, and pain specialists.

All of these experts have experience and training in the evaluation and treatment of patients with MS.



Quality of Life Visit Details

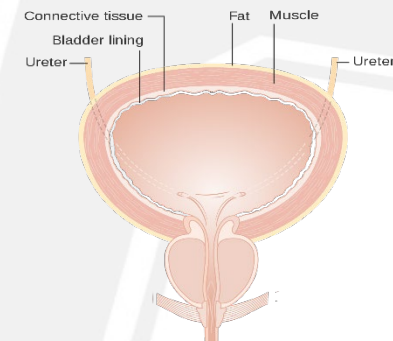
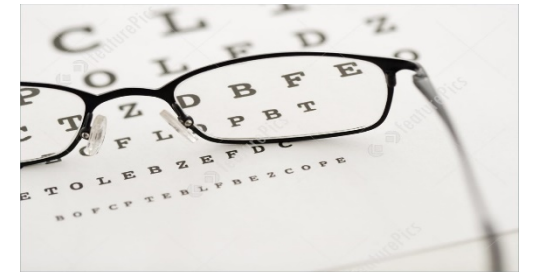
- Meet with provider and discuss goals
- Review MS/ disease education, process details and DMT details
- Complete MSQLI screening tool/ MSQOL-54
- Complete other screening and baseline testing, labs, bladder scanning, OCT, BMI
- Discuss recommendations for diet, exercise and supplements
- Referrals to specialists as needed for example, Cognitive testing, Physical therapy, Assistive Devices, Urology, Clinical Pharmacy, Sleep Clinic
- Regular follow up to assess progress and redirect as needed



MSQLI Screening tool NMSS

List of Instruments Making up the MSQLI (in order of administration)

- Health Status Questionnaire (SF-36) - 36 items
- Modified Fatigue Impact Scale (MFIS) - 21 items*
- MOS Pain Effects Scale (PES) - 6 items
- Sexual Satisfaction Scale (SSS) - 5 items
- Bladder Control Scale (BLCS) - 4 items
- Bowel Control Scale (BWCS) - 5 items
- Impact of Visual Impairment Scale (IVIS) - 5 items
- Perceived Deficits Questionnaire (PDQ) - 20 items*
- Mental Health Inventory (MHI) - 18 items*
- MOS Modified Social Support Survey (MSSS) - 18 items*



Taking A Multidisciplinary Approach

- The best way to achieve QOL for our patients with chronic disease is to utilize a multidisciplinary approach
- Screening tools completed during QOL visits help identify areas of deficit and help direct referrals to appropriate specialties eg. the MFIS and PHQ-9. The MS QOL54. Screening tools provide a metric to measure outcomes.
- Referrals help patients receive the best care for multisystem disease related conditions, and this improves QOL
- Multidisciplinary Clinics- Patients see imbedded specialists on the same clinic day for example, sleep, cognitive testing, Physical Therapy, Clinical Pharmacy, Cognitive Talk therapy



Multidisciplinary Care Team

Imbedded specialists in clinic at Martha Morehouse Pavilion

Personalized, multi-disciplinary comprehensive care

Clinic team

- Nurse practitioner
- MS Nurse
- Clinical care coordinator
- Social work
- Pharmacist
- Infusion center
- Dietician/nutritional care
- Recreational therapy



Clinical care



Education



Research



Rehab



PMNR



Infusion



Mental health



Pain medicine



Urology



Nutrition



Pharmacy



Community



Outreach



Recreation



Advocacy



Comprehensive Care is the best approach

Multidisciplinary Care is a Focus at The Ohio State University

Why is comprehensive care the best approach for MS?

- Evidence suggest that multi-dimensional team approach is the most effective and efficient way of treating persons with MS
- Barriers to care
 - Lack of communication between providers
 - Lack of continuity of services
 - Variability in availability, access and quality of care
 - Insufficient psychological counseling
 - Lack of patient education



Comprehensive Care Teams

Who is in the comprehensive care team?

1. A well-informed person with MS
2. Families and care givers
3. An integrated network of care partners



The Ohio State University Care Team



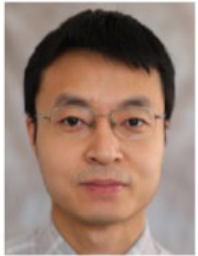
The importance of specialized, personal care

New Members of the Care Team



Emily Harrington, MD

Dr. Harrington is a physician scientist who specializes in the care and treatment of multiple sclerosis patients. She is particularly interested in finding better treatments for progressive multiple sclerosis and enhancing myelin repair with the hopes of preventing disability and neurodegeneration. Dr. Harrington obtained her medical and graduate training at the University of California San Francisco and her multiple sclerosis fellowship at Johns Hopkins. She is originally from Kansas City. She is excited to be a part of the Ohio State multiple sclerosis team.



Yinan Zhang, MD

Dr. Zhang will be joining the Multiple Sclerosis and Neuroimmunology Center at the Ohio State Wexner Medical Center in September from New York City, where he received his fellowship training in MS at Mount Sinai. He completed his medical school and neurology residency at the University of Texas Southwestern Medical Center in his hometown of Dallas. Dr. Zhang values getting to know his patients over time and finding the best treatment strategies for each person's unique needs and disease characteristics. His research focuses on aging and MS, including how biological changes during aging contribute to evolution of the disease. Dr. Zhang enjoys spending his free time with his family and building custom Lego creations.



Meena Khan, MD

Dr. Khan is a neurologist and associate professor of Clinical Medicine at The Ohio State University Wexner Medical Center. She is the program director for the Sleep Medicine Fellowship program as well as co-director of the annual Ohio State Sleep Symposium. Her clinical interests center on sleep in neurological disease. She manages the sleep medicine neuromodulation program for sleep disordered breathing and has a clinic specifically devoted to sleep issues in those with multiple sclerosis.

Summary

- Achieving Quality of Life is an achievable goal and priority in comprehensive patient care. Focus on treating the disease process and symptoms but also on the whole individual.
- The Quality of Life Clinic at OSU can help MS patients identify areas of need, and direct patients to the MS Multidisciplinary Clinic
- Utilizing techniques to achieve wellness can promote QOL. Diet, exercise, mental health, DMT
- Wellness should be approached using evidence based practice, diets and supplements should be based in science, backed by evidence and discussed with your provider
- QOL can be best achieved by taking a multidisciplinary approach to patient care such as MSMDC Friday's at Martha Morehouse





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What is MS?

Multiple Sclerosis is a complex disease process in which an abnormal immune mediated response occurs in the body's immune system, attacking the central nervous system causing focal demyelination, inflammation and varying degrees of neuro-axonal loss that results in neurological dysfunction. It is a chronic disease affecting a demographic from 18-60, with a multifactorial combination of environmental and genetic risk factors. These include gender, ethnicity, latitude and preventable factors such as obesity, smoking and low vitamin D. Many consider this to be an autoimmune disease, however no specific antigens have been identified in MS.

Objectives

- Identify Quality of Life and Wellness as it pertains to living with chronic disease and Multiple Sclerosis
- Discuss Diet
- Discuss Supplements frequently asked about in MS clinic
- Multidisciplinary Approach
- Quality of Life Visits





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Can Diet Effect MS?

Diet can positively affect the overall health of an individual living with chronic disease. Poor diet, obesity, low vitamin D and smoking can increase the risk of developing MS due to the pro-inflammatory effects of this type of lifestyle. Once the abnormal immune response has started however, there is no evidence to suggest that any diet can reverse this process. Making changes such as eliminating food allergens, eating a healthy balanced diet, smoking cessation, belly fat reduction and vitamin D supplementation can have very significant effects on reducing inflammation. This is important as there is an inflammatory component in MS as previously discussed. Wellness should be approached using evidence based practice, diets and supplements should be based in science, backed by evidence and discussed with your provider

Questions to ask before starting a Diet or Supplement;

Is it Harmful?

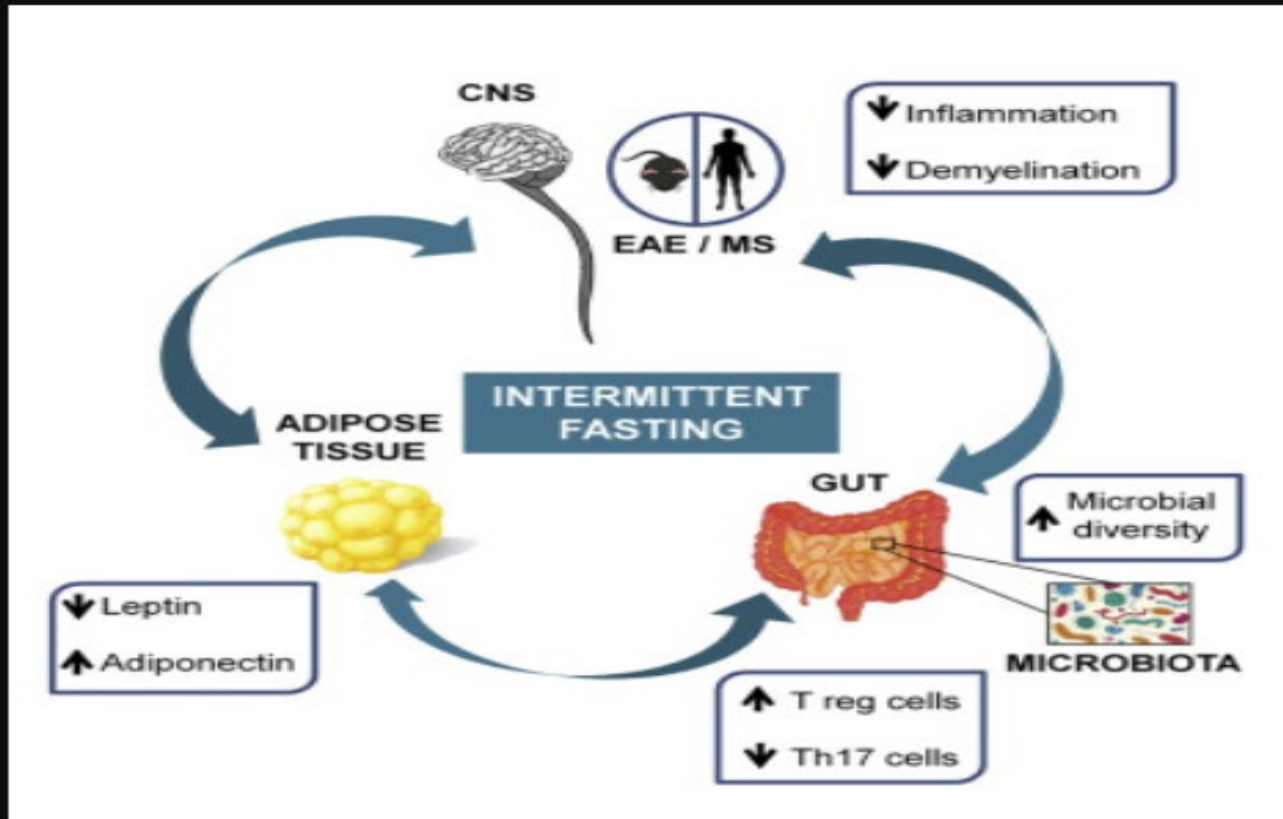
Is it cost prohibitive?

Is there evidence to support its use?

What is the best diet? Investigating popular trends

- This is a discussion regarding popular diets, **we are not endorsing or recommending any specific diet**, please discuss individually with your provider.
- **Mediterranean Diet**- vegetables, fruits, whole grains, beans, nuts and seeds and olive oil. No refined foods, added sugars or processed meats
- **Anti-inflammatory Diets**- omega 3 fatty acids, long chain fatty acids
- **Wahl's Protocol**- Dr. Terry Wahls. Physician with SPMS U of Iowa. Increase cellular function and ATP production. Diet and exercise protocol.
- **Intermittent Fasting/ Calorie Reduction**-. Intermittent fasting has recently received a lot of attention as a tool to reduce inflammation. There are some good results in MS trials regarding reduction of inflammatory markers and reduction of adiposity (body fat) which is pro-inflammatory. There are many ways to achieve intermittent fasting results with modified plans, strict 72- hour fasting is not the only method to achieve results
- **Individualized Diet**- based on food sensitivity testing, allergy testing, elimination diets. Example gluten allergy.

Intermittent Fasting and Gut Microbiome



Individualized Diet

- **Balanced diet with RDA of calories from protein, carbohydrates and fat. Reduce/avoid processed food, added sugar, saturated fats and processed meats. Heart healthy diet.**
- Food Sensitivity Testing- Blood test, skin test
- Elimination Diets
- Food Journaling
- Gut Microbiome- Pre and Probiotics. Increase anti-inflammatory cytokines and T-regs. Keep tight gut junctions. 8-12 week adherence
- Consulting GI, Dietician when needed
- Interpreting results and formulating diet plan based on allergies, BMI and caloric RDA

Supplements frequently asked about in MS Clinic

- **Vitamin D-** Downregulates inflammation in CNS. Check serum levels and prescribe appropriately. Ample evidence in numerous trials.
- **Alpha Lipoic Acid-** some evidence in reduction of atrophy in progressive MS patients
- **Biotin-** Recent studies do not support any change in disability. MS SPI, SPI 2 trials
- **Turmeric Curcumin-** studies show curcumin exhibits neuroprotective effects in MS through anti-oxidant, anti-inflammatory, anti-proliferative and anti-differentiation mechanisms. Psoriasis trials. More MS trials are needed.
- **Antioxidants-** Reduce cellular oxidative stress. Examples ; Vitamin C, Vitamin E, Carotenoids
- **Pre and Probiotics** – Evidence suggests probiotic consumption via gut microbiome changes can have beneficial effects on improving immune/inflammatory response in MS.



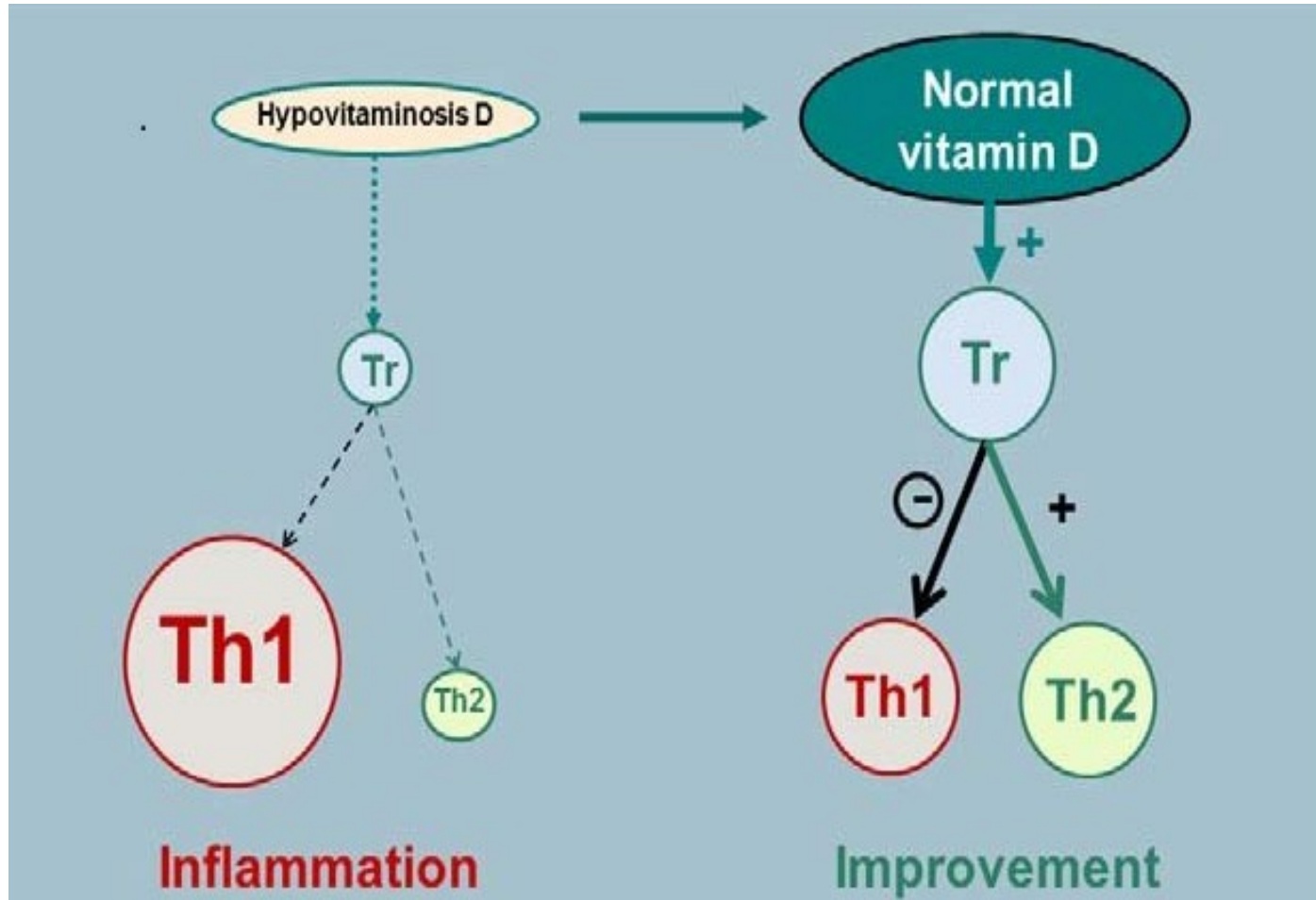
Wellness

- Defined by the World Health Organization as “a state of complete physical, mental and social well being and not merely the absence of disease or infirmity”
- Defined by Britanica as “a state of being in good health, both physically and mentally, and of being free of and not at risk for illness.”
- Defined by CDC as “a state that integrates mental health (mind) and physical (body) resulting in more holistic approaches to disease prevention and health promotion.”

Vitamin D

- Hypovitaminosis D is linked to higher disease activity
- Risk factor for development of MS
- Innate immune response promoted and adaptive response muted resulting in reduced cytokine production mediated by Type 1 T helper cells
- Provider will determine recommended daily dosage
- Monitor Serum levels regularly, avoid toxicity

Vitamin D



Biotin

- Biotin is thought to enhance neuronal and oligodendrocyte energy production to improve cellular function, repair or survival
- Biotin augments ATP production and theorized to enhance myelin repair or synthesis
- SP1 SP2 Trials in MS failed to show significant evidence to support use , no change in disability noted with high dose biotin
- High dose biotin can skew important lab results such as thyroid test as it can effect study assay
- **No current evidence to support high dose biotin**

Domains of Wellness



Alpha Lipoic Acid

- ALA is thought to limit the transmigration of inflammatory T cells and monocytes into the CNS
- In mouse models with EAE, ALA suppressed the time to development of symptoms and slowed progression of symptoms
- MS trial in SPMS showed some good results in reducing whole brain atrophy
- Reduces oxidative stress
- Frequently used in diabetic neuropathy
- Found in spinach, broccoli and tomatoes
- **Current ongoing studies in MS**
- **No consensus in current evidence to support its use**

Turmeric Curcumin

- Inhibits pro-inflammatory cytokines
- Reduces infiltration of inflammatory cells into the CNS
- Modulates cell cycle regulatory proteins, enzymes, cytokines and transcription factors in CNS-related disorders including MS
- **Natural anti-inflammatory**
- Bioperine/ Black pepper added to Turmeric increases gut bioavailability by prolonging glucuronidation
- Take separately from other medications
- Often used in arthritis and skin conditions such as psoriasis
- **No current significant evidence to support its use in MS, more studies needed**



Antioxidants

- Examples Vitamin C , Vitamin E , CoQ10
- Reduce cellular oxidative stress
- Evidence of OS found during active relapses, in active inflammatory lesions and chronic plaques
- Mouse models in EAE demonstrated evidence of OS in the brain
- The brain is more susceptible to OS
- Healthy lifestyle changes such as healthy diet and regular exercise also reduce OS
- Used in combination with DMT

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