
Living Well with PI: An Integrative Health Approach to Pain Management

Maeve O'Connor FACA AI FAAAAI FACP

Medical Director, Integrative Allergy & Immunology Care, LLC

Medical Director, Allergy Asthma & Immunology Relief (AAIR)

Medical Director, Allergy Asthma & Immunology Research Institute (AAIRI)

Chief Medical Officer, Consortium of Independent Immunology Clinics

Charlotte, NC

Learning Objectives

- Describe PI and Pain
- Understand the concepts that define Integrative Medicine
- Define an integrative approach to provide optimal PI care
 - Traditional, complementary and spiritual aspects
- Understand the "mind/body" concept
- Open the Integrative Medicine Toolbox
- Understand alternative & complementary therapeutic options

Prognosis of PID

- Rarely need make major life changes in response to the diagnosis
- Modifications are needed
- Most people with PI are able to live full and (relatively) normal lives
- Adopting a healthy lifestyle is the key

Primary immunodeficiency (PI) and Pain

- In PI, the immune system doesn't work properly, which can make people more likely to develop painful conditions.
- PI patients have chronic conditions → both acute and chronic pain
- Activation of neurogenic inflammation through innate immunity
 - Key role in initiating and maintaining neuropathic pain
- Some features of bacteria/viruses resemble those of nerve cells
 - Dysregulated immune system may not be able to distinguish
 - Neuropathic pain results

Primary immunodeficiency (PI) and Pain

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Autoimmune diseases:

- CVID → Polyarthritis
- Painful & swollen joints in the knees, ankles, elbows, or wrists.

Infections:

- Pink eye, sinus infections, thrush
- URI/colds, gum disease, cavities
- Herpes simplex or varicella-zoster
- Recurrent deep skin or organ abscesses

Primary immunodeficiency (PI) and Pain

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GI disorders

- Celiac disease, IBDs, and Pernicious anemia
- Uncontrolled Gut inflammation/ Disrupted microbiome

Malignancies

- Pain from the cancer or the cancer treatment

Chronic inflammation

- Enlarged spleen
- Enlarged lymph nodes/swollen glands

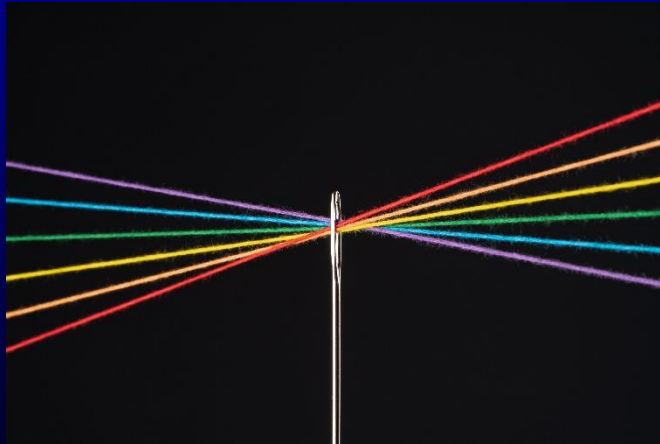
Western/Traditional Medicine

- A system in which healthcare professionals treat symptoms and diseases using drugs, radiation, or surgery
 - Doctors, nurses, pharmacists, and therapists.
- **AKA :**
 - *Allopathic*
 - *Biomedicine*
 - *Conventional*
 - *Mainstream*
 - *Orthodox*

The Defining Principles of Integrative Medicine



- Partners in Healing Process
 - Patient & practitioner
- Inclusive of **all** influences on a person's individual health



Physical

Emotional

Social

Mental

Spiritual

Environmental

Paramount to Integrative Medicine

- Shared Decision Making
- Health promotion
- Prevention of Illness & Pain
 - *When possible*



Integrative Medicine

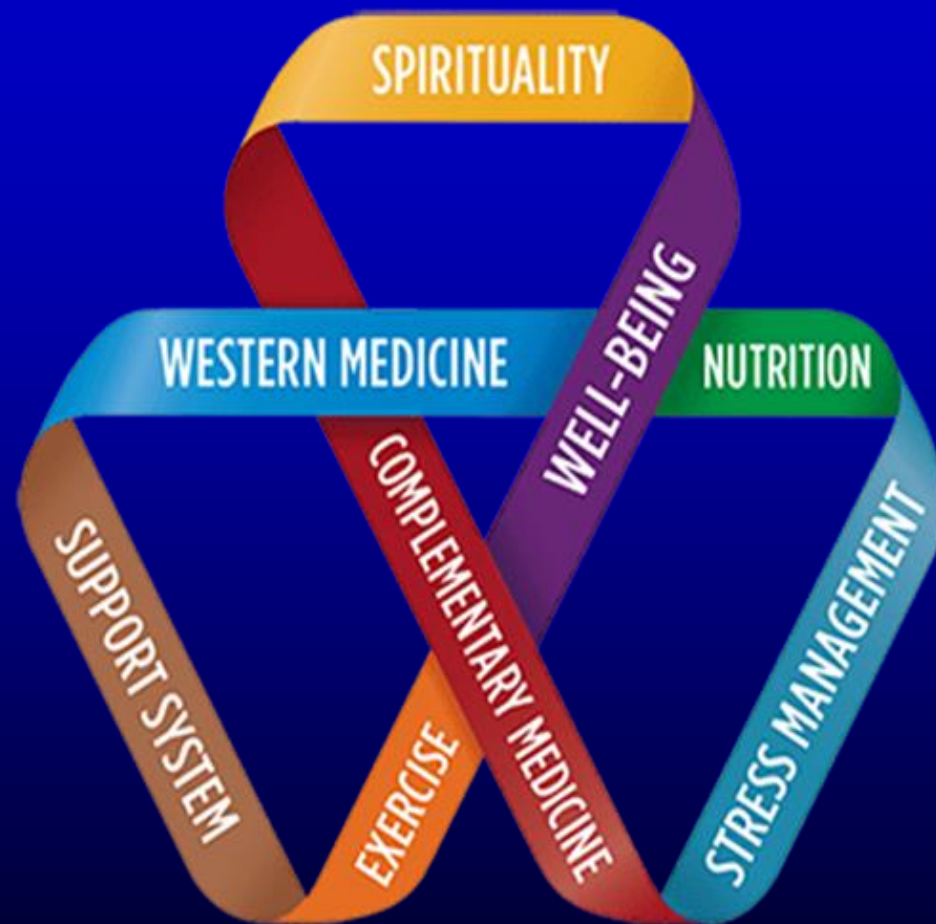
Therapeutic goal → treating the *whole* patient

- Integrative medicine neither rejects conventional medicine nor accepts alternative therapies uncritically
 - Use all available evidenced-based therapy
 - Conventional, complementary and/or “alternative”
 - Good medicine is based in good science
- This approach to care is recorded from earliest medical history

“It is far more important to know what person the disease has than what disease the person has.”

Hippocrates

Integrative Medicine and Living Well with PI



Integrative Medicine Toolbox

- Acupuncture
- Breathing Techniques
- Mindfulness
- Nutrition
- Supplements
- Exercise
- Massage
- Yoga
- Biofeedback



Acupuncture

- Traditional Chinese Medicine
>2500 years use of acupuncture
- NIH recognizes Acupuncture as
“an effective adjunctive therapy for
multiple indications”
- Benefits difficult to measure
 - Report decreased chronic pain, relaxation,
increased energy
- Low Risk
- Pain → soreness or bruising
- Infection-→Single-use Disposable needles



Acupuncture



Acupuncture points in all areas of body. Appropriate points may be far removed from the area of pain.

- **Needle insertion**

- Needles inserted to various depths at strategic points
- Thin → insertion usually little discomfort if even felt.

- **Needle manipulation**

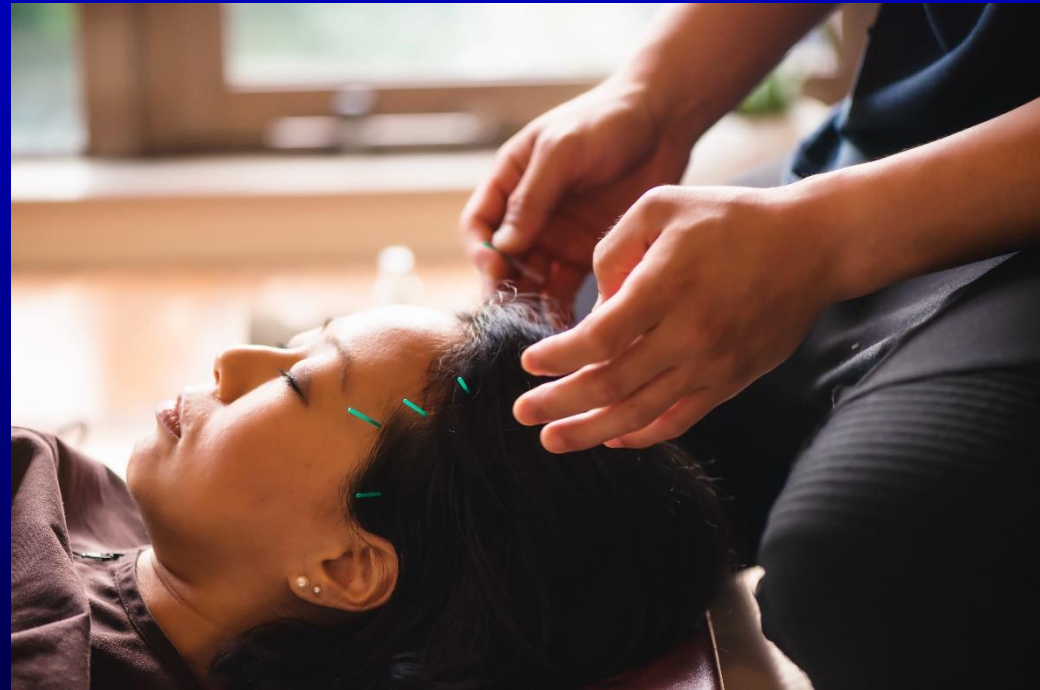
- May gently move or twirl the needles after placement or apply heat or mild electrical pulses to the needles.

- **Needle removal**

- Needles remain in place for 10 to 15 minutes while patient lies still and relaxes
- Usually no discomfort when the needles removed

Acupuncture for Chronic Pain: Individual patient data meta-analysis

- Systematic review to identify randomized trials of acupuncture for chronic pain in individual patients
- Effects of acupuncture persistent over time
- Benefits could not be explained away by the placebo/sham effect.
- Conclusion:
- Acupuncture is effective for a number of chronic pain conditions.



Fight-or-Flight Response <-> Relaxation Response



Natural stress response that's designed to help you deal with dangerous situations

Suppresses immune system and can cause high blood pressure, depression, and anxiety.

Sympathetic nervous system controls stress response.

Parasympathetic controls rest & relaxation response.

Activate one, suppress the other

Mindful breathing effective at causing the relaxation response.

Interrupts stress response with a profound sense of rest.



4-7-8 Breathing

”Natural tranquilizer for the nervous system.”

Andrew Weil, MD

Takes the shallow, oxygen poor breathing you normally do when stressed out, and turns it
upside down



4-7-8 Breathing



- Stress->under-breathing -> *mild hypoxia*
- Oxygen deprivation->build up excess carbon dioxide in tissues--> oxidative stress, inflammation and acidification
Foundations for disease and pain!

4-7-8 Breathing

- Breathe in through your nose for a count of 4
- Hold your breath for a count of 7
- Release your breath from your mouth with a whooshing sound for a count of 8
- Without a break, breathe in again for a count of 4, repeating the entire technique 3-4 times in a row, then resume normal breathing and activity.

4-7-8 Breathing

- Safe and Effective:
 - Only do it for four cycles in a row in the beginning.
 - Work up to eight cycles
 - May feel lightheaded at first, but this will pass

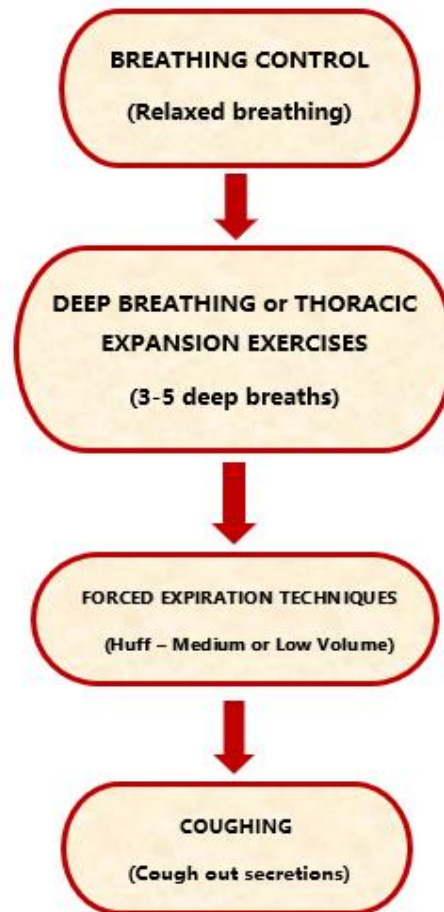
Active Cycle Breathing Technique (ACBT)



- Patient directed
- Easy to incorporate into practice
- All ages capable
- Safe

4 Basic Step of ACBT

Steps of Active Cycle of Breathing Technique



Active Cycle Breathing Technique (ACBT)

- Helps clear the airway of secretion
- Improves lung function
- Reduces risks of infection
- Improves effectiveness of cough



Health Benefits of Breathing Well

Reduced anxiety. A study of senior citizens showed decreased anxiety after two months of deep breathing exercises

Lower blood pressure. Slow deep breathing for five minutes has been shown to reduce blood pressure and heart rate

Improved sleep. Practicing deep, slow breathing techniques triggers relaxation response

Less pain. A study of 16 healthy people found that those who practiced relaxed deep breathing experienced less pain than those who practiced deep breathing that required a lot of sustained attention. Both groups experienced less tension, anger, and depression.

Improved concentration. A 2017 study examined the effect of eight weeks of deep, slow, abdominal breathing on attention, emotions, and stress levels. After training, the people in the deep breathing group performed better on tests of attention and had fewer negative emotions.

Mindfulness Based Stress Reduction

Mindfulness training

- Develop nonreactive awareness of distinguishing
 - Experience : *thoughts , feelings*
 - Sensations : *dyspnea*
- Meditation with focus on controlled breathing
- Stretching to develop awareness during movement

- Evidence suggests that a higher level of mindfulness
 - Decreases anxiety & depression
 - Decreases chronic pain

General Nutrition Considerations

- Poor nutrition → many illnesses
 - Infections for which the PID individual is already at risk
 - Infections → Pain
- Good Nutrition Basics
 - Increase Variety of Foods
 - Maintain ideal body weight
 - Adequate starch and fiber
 - Limiting the intake of fat, cholesterol, sugar, salt and alcohol.
 - Organic, *when possible*

General Nutrition Considerations

- Use of herbal supplements is common
 - Not considered “drugs” and are not FDA regulated
- Some scientific evidence of boosting immune system
- Caution should be used
- Can be harmful or interact adversely with medicines
- Healthcare provider’s opinion should always be sought
- Vitamins, electrolyte supplementation or probiotics ~appropriate
 - No substitute for a healthy, balanced diet.

Nutrition Supports Optimal Health in PI

- Diet plays an important environmental role in positively or negatively affecting both gut microbiota and the immune system
- An anti-inflammatory diet helps manage inflammation and may boost the immune system
 - Includes fruits, vegetables, whole grains, and unsaturated fats, and limits red meat, dairy, alcohol, and processed foods
- Oxidative stress is unavoidable; antioxidant foods and supplements support the functioning of the immune system to
- Saturated fats elicit an inflammatory cascade

Anti-Inflammatory Diet

- Fish oil, in capsule or liquid form
 - Two to three grams a day of a product containing both EPA and DHA
 - Molecularly distilled products certified to be free of heavy metals/contaminants
 - Plant-based if vegetarian/vegan
- Ginger and tumeric → Supplement as tolerated
- CoQ10: 60-100 milligrams of a soft gel
- **Water**
 - Drink pure water, or drinks that are mostly water
 - tea, very diluted fruit juice, sparkling water with lemon
 - Use bottled water or get a home water purifier

Anti-Inflammatory Diet: General Health Considerations

- Variety
 - Colorful Plate
- Fresh food whenever possible
- Avoid consumption of processed foods
- Avoid fast food
- Eat an abundance of fruits and vegetables
- Avoid hormones, antibiotics, GMOs

Anti-Inflammatory Antioxidants

Flavonoids

- Support hydration and decrease inflammation of airway surfaces
- Prevention of skin inflammation

Vitamin C

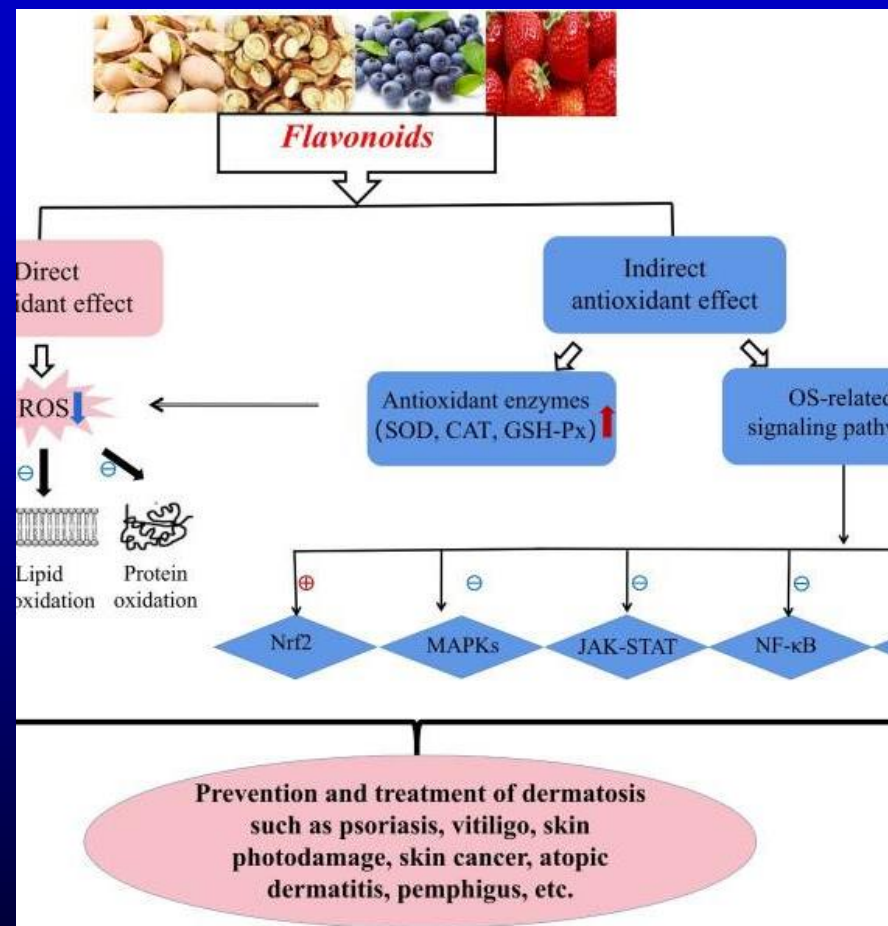
- Decrease inflammation by impeding PGE2

Carotene

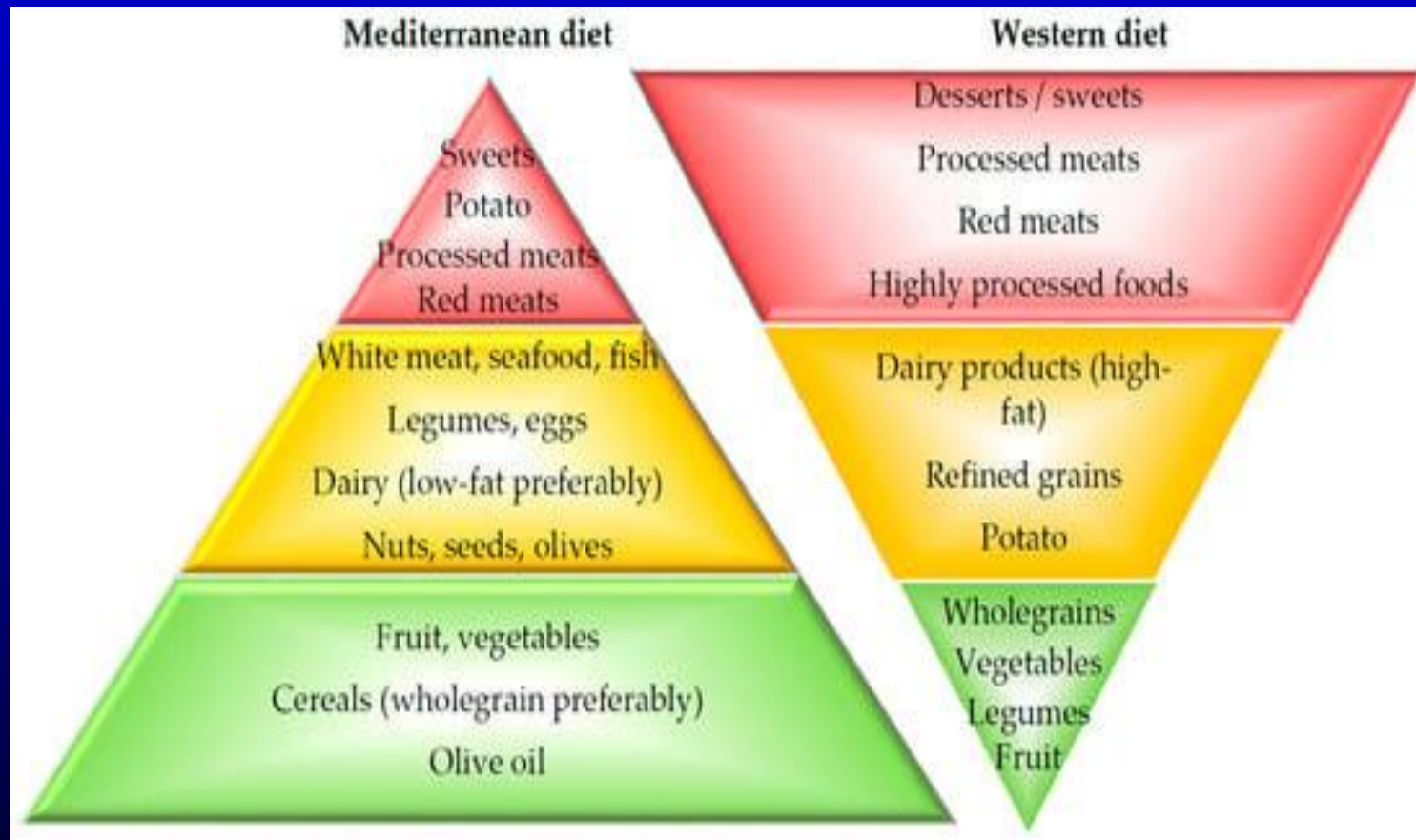
- Improves lung function

Selenium

- Aids in preventing lipid peroxidation



Mediterranean Diet vs Western Diet



Western Diet

- Convenient
 - Fast Food
 - McDonalds
 - Frozen Meals
 - Microwave Meals
 - Pizza
- Highly Processed
 - Sweets
 - Cookies
 - Ice Cream
 - Processed meats
 - Fish Sticks
 - Chicken Nuggets



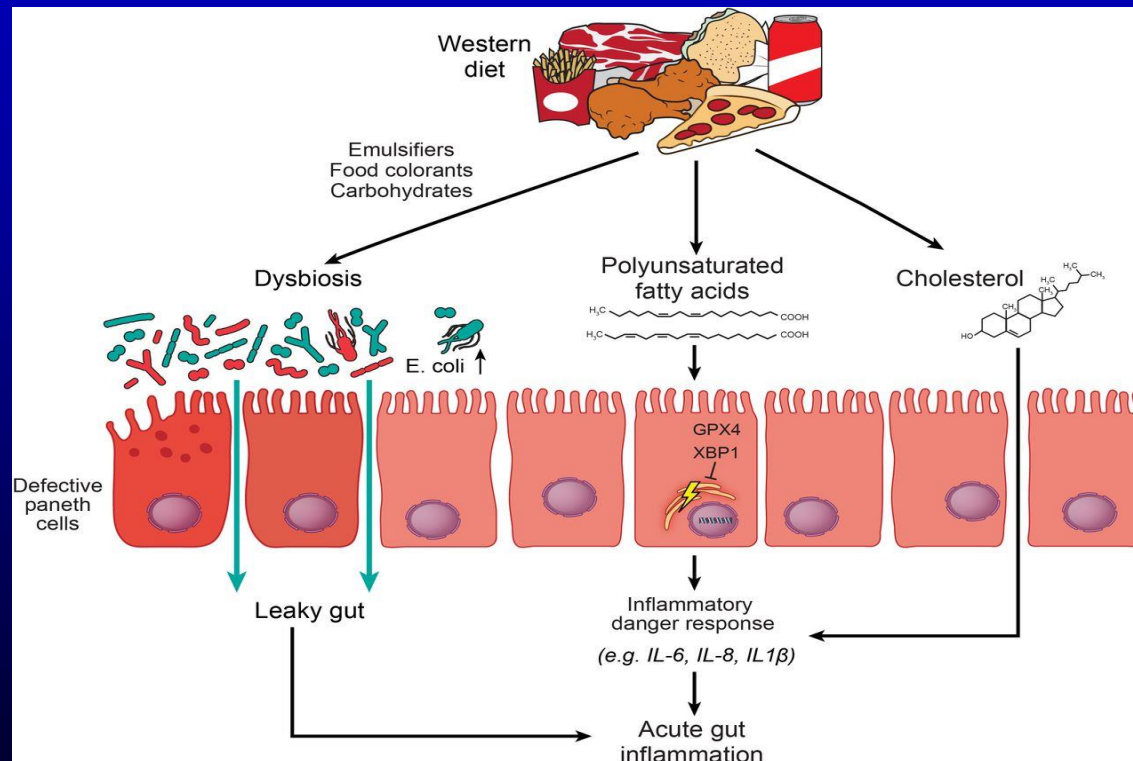
Mediterranean Diet



- Fresh
 - Farm table
 - Eggs
 - Seasonal Vegetables
- Whole Foods
 - Grains
 - Barley, Steele Cut Oats
 - Nuts
 - Almonds
- Fruits
 - Apples, Avocado
- Some Meats
 - Cold Water Fish
 - Tuna
 - Limited Chicken

Western Diet

- Impairs epithelial immune responses
- Promotes dysbiosis and inflammation



GUT

Nutrition/Well-Being

- Avoid Alcohol
 - Liver needs to be preserved
 - Fragmented sleep
- Avoid Tobacco
 - Already enough respiratory issues, risk of malignancy
 - Vaping is NOT safer!!!!
- Avoid Recreational Drugs, unless prescribed
 - Impairs clear thinking, consciousness
 - Pro-inflammatory

General Health Considerations: Nutrition

- Need Help?
 - Seek a nutritionist
 - Farmer's Market
 - Healthy recipes on line
 - New hobby for stress relief with maximum health benefits?
 - Cooking
 - Gardening
 - Hosting healthy dinner parties/picnics

Educate Self for Improved Health and Less Pain

- Address comorbid psychological issues associated with PI
 - Support groups available
 - Exercise regularly when it can be done safely
- Take a leadership role in YOUR healthcare
 - Ask for patient directed healthcare objectives through education
 - Discover limitations safely
 - Always tell the truth about health
- Create some time for relaxation and rest
 - Healthy sleep habits (no computers, books or tv in bed)
 - Spend a few minutes each day quietly to self
 - Take time to decompress after stressful events

Exercise

- Physical activity is encouraged for all people
- Healthy Mind AND Body
- Regular exercise is an excellent stress and anxiety reducer.
 - Swimming, biking, running and walking promote lung function, muscle development, strength and endurance
- Organized sports excellent outlet for children who struggle with coping with their illness/pain
 - “just a regular kid”
- Some exercise may be contraindicated for people with specific Immunodeficiencies.
 - Wiskott-Aldrich Syndrome
 - No contact sports
 - Chronic Granulomatous Disease (CGD)
 - Don't swim in the ocean or fresh water

Sleep Habits Impact Pain

- Erratic sleep patterns → negative effects on the immune system
- Go to sleep and wake up at roughly the same time each day
- No late nights as no “Make-up” Sleep
- Minimize consumption of caffeine or alcohol in the evening
- No heavy meals in the evening or late night snacking
- Minimize potential disturbances during the night
 - TV, tablets, phones
- No long naps during that interfere with regular sleep schedule

Stress and Pain in PI

- **Stress---→ SICKNESS**
- **Chronic Illness→ Stress**
- Negatively affects the normal functioning immune system
- Reducing stress can improve immune function
 - Physical activity
 - Proper Sleep
 - Massage and psychologic therapy
 - Biofeedback
 - Meditation
 - Hobbies
 - Social interactions with others
 - Volunteering

Useful Resources

ASK FOR HELP!

- IDF
- ACAAI-College
- AAAAI-Academy
- Local Support Groups
- **Your PCP**
- Your Immunologist
- Your Family and Friends

Future Topics

- Biofeedback
- Meditation
- Yoga
- Sleep Hygiene
- Exercise Plans
- Supplements
- Medical THC
- Massage
- Yoga
- Pain Management Referral-PMNR MD

Conclusions:

Integrative Health Approach to Pain Management in PI

- Many trials, mostly small, promising results and outcomes
- Need more controlled trials with Integrative Medicine and PI
- IM therapeutics improve outcomes when used in conjunction with conventional treatments
- Harmless approaches *should be incorporated*
 - Breathing, meditation, nutrition
- Objective & statistically significant data ->utilize IM approaches effectively
- Integrative Medicine approaches can improve pain in PI

Thank You

**A happy heart is good medicine
and a cheerful mind works healing,
but a broken spirit dries up the bones.**

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