

Answers. Advocacy. Action.

LUPUS

&you

by Lupus Foundation of America

Pain & Fatigue

The program will begin shortly!

Thank You For Joining Us!

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Pain & Fatigue

APRIL 8, 2025

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Agenda

7:00

Welcome, LFA Overview, Programs & Services, Khadija Dantata, MD, MHA, LFA

7:15

Pain in SLE, Dr. Daniel J. Clauw, Professor of Anesthesiology, Internal Medicine (Rheumatology) and Psychiatry, The University of Michigan

7:40

Management Strategies for Fatigue in Lupus, Dr. Julius Birnbaum, Rheumatologist, University of Pittsburgh Medical Center

8:05

Questions + Answers, All Panelists

8:30

Closing, Khadija Dantata, MD, MHA, LFA

Daniel J. Clauw, MD

Internal Medicine, Rheumatology, Professor of Anesthesiology, Internal Medicine (Rheumatology), and Psychiatry Director, Chronic Pain and Fatigue Research Center, The University of Michigan

Julius Birnbaum, MD

University of Pittsburgh Medical Center

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Housekeeping Items

• Ask questions!

Submit questions for our speakers via the Q+A Feature.

• Reminder:

The content shared today is for educational and informational purposes only. Consult with your doctor/health care team for medical advice.


• Re-watch!

Tonight's webinar will be recorded for you to view later at: Lupus.org/LupusAndYou

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Take Our Poll!

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Our Vision

A life free from lupus.

Our Mission

The Lupus Foundation of America is dedicated to improving the quality of life for all people affected by lupus through programs of research, education, support, and advocacy.

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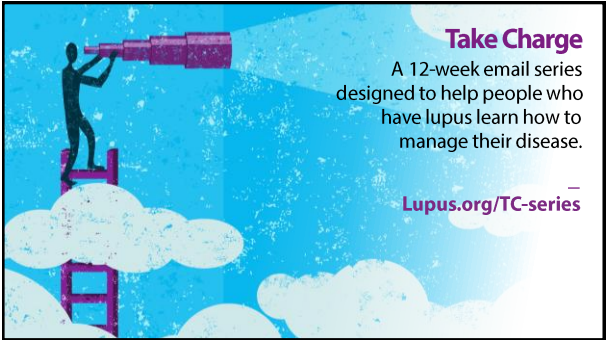
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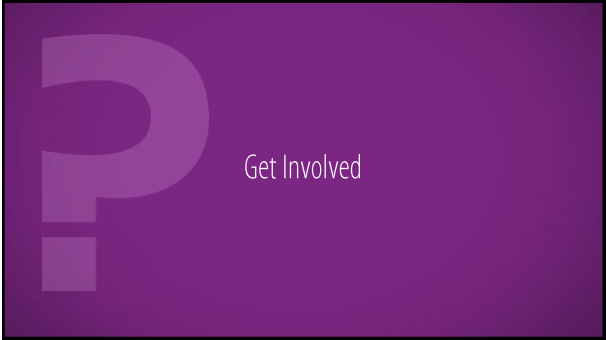
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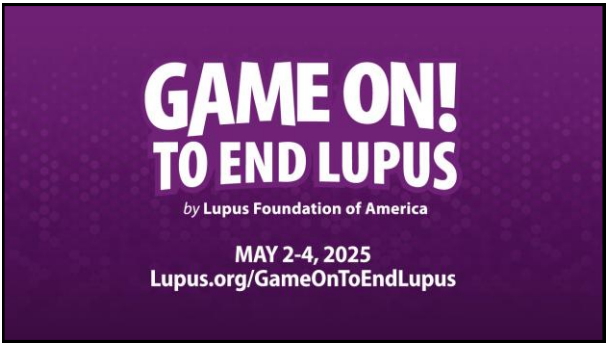
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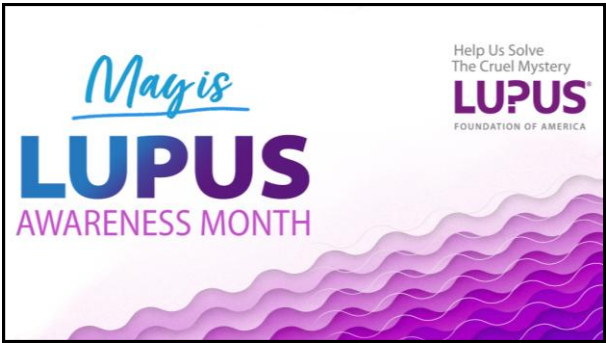
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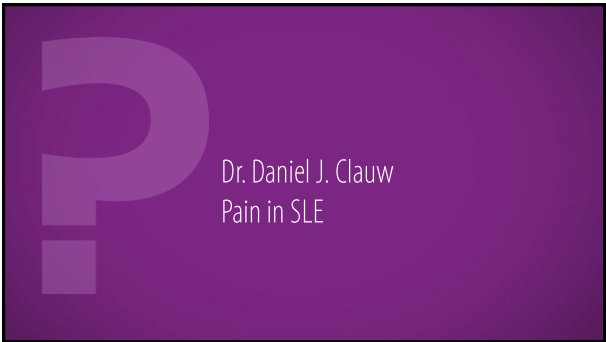
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Pain in SLE

Daniel J. Clauw M.D.
dclauw@umich.edu
Professor of Anesthesiology, Medicine (Rheumatology), and Psychiatry
Director, Chronic Pain and Fatigue Research Center
The University of Michigan

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Disclosures

- Consulting
 - Pfizer, Tonix, Lilly, Merck, Axsome, Virios, Swing
- Litigation
 - Testified against opioid manufacturers and distributors in State of Oklahoma and Florida
 - Testified in defense of vaccine manufacturers

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Pain in SLE

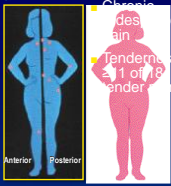
- Define new terms
 - Nociplastic pain
 - Chronic overlapping pain conditions
 - Primary pain
 - Type 1 vs 2 SLE
- What is known about pain in SLE?
- Treatment implications

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Evolution of Thinking Regarding Fibromyalgia

American College of Rheumatology (ACR) Criteria

- Discrete illness
- Focal areas of tenderness
- Pathophysiology poorly understood and thought to be psychological in nature



- Final common pathway (i.e. pain centralization)
- Part of a much larger continuum
- Not just pain
- Pathophysiology fairly well understood and is a CNS process that is independent from classic psychological factors

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Mechanistic Characterization of Pain

Variable degrees of any mechanism can contribute in any disease

	Nociceptive	Neuropathic	Centralized/Nociplastic
Cause	Inflammation or damage	Nerve damage or entrapment	CNS or systemic problem
Clinical features	Pain is well localized, consistent effect of activity on pain	Follows distribution of peripheral nerves (i.e. dermatome or stocking/glove), episodic, lancinating, numbness, tingling	Pain is widespread and accompanied by fatigue, sleep, memory and/or mood difficulties as well as history of previous pain elsewhere in body
Screening tools		PainDETECT	Body map or FM Survey
Treatment	NSAIDs, injections, surgery, ? opioids	Local treatments aimed at nerve (surgery, injections, topical) or CNS-acting drugs	CNS-acting drugs, non-pharmacological therapies
Classic examples	Osteoarthritis Autoimmune disorders Cancer pain	Diabetic painful neuropathy Post-herpetic neuralgia Sciatica, carpal tunnel syndrome	Fibromyalgia Functional GI disorders Temporomandibular disorder Tension headache Interstitial cystitis, bladder pain

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Chronic Pain 2

Nociplastic pain: towards an understanding of prevalent pain conditions

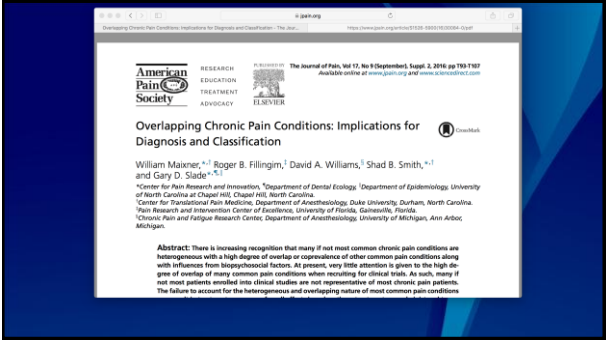
May-Alex Fleicher¹, David P. Cohen², David C. Stone, Geoffrey L. Williams, David C. Stone, William H. Miller

Nociplastic pain is the semantic term suggested by the international community of pain researchers to describe a third category of pain that is mechanistically distinct from nociceptive pain, which is caused by engaging inflammation and damage of tissues, and neuropathic pain, which is caused by nerve damage. The mechanisms that underlie this type of pain are not entirely understood, but it is thought that engagement of CNS pain and sensory processing and altered pain modulation play prominent roles. The symptoms described in nociceptive pain include widespread pain that is more widespread in nature, as both, thus would be expected given the nature of identifiable tissue or nerve damage, as well as other CNS-derived responses, such as fatigue, sleep, memory, and mood problems. This type of pain can occur in isolation, or often occurs in conditions such as fibromyalgia or tension-type headache, or as part of a mixed pain state in combination with ongoing nociceptive or neuropathic pain, as might occur in chronic low back pain. It is important to recognize this type of pain, since it will respond to different therapies than nociceptive pain, with a decreased responsiveness to peripherally directed therapies such as anti-inflammatory drugs and opioids, surgery, or injections.

Introduction

Recent evidence suggests that nociplastic pain is a distinct entity, occurring in isolation or as a comorbidity in individuals with

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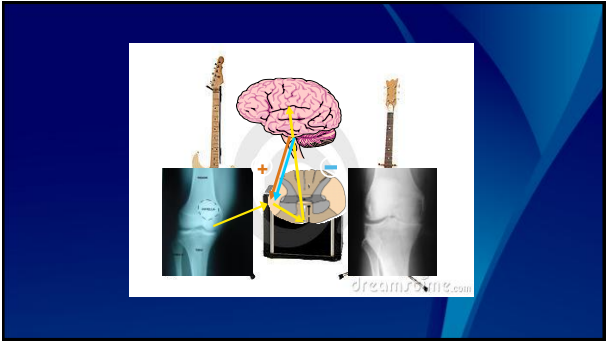


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Chronic Overlapping Pain (or Primary Pain) Conditions

- Most highly prevalent pain conditions in individuals under age 50
 - Headache
 - Fibromyalgia (fibrositis)
 - Irritable bowel (spastic colitis)
 - Temporomandibular disorder (TMJ)
 - Bladder pain syndrome (interstitial cystitis)
 - Low back pain
 - Endometriosis
 - Vulvodynia (vulvar vestibulitis)
 - Chronic fatigue syndrome
- Same central mechanisms play significant roles in all pain conditions, even those with known peripheral contributions

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Fibromyalgia-ness

- Term coined by Wolfe to indicate that the symptoms of FM occur as a continuum in the population rather than being present or absent ¹
- In rheumatic disorders such as osteoarthritis, rheumatoid arthritis, lupus, low back pain, etc. this score is more predictive of pain levels and disability than more objective measures of disease ^{2,3}
- Domain overlaps with somatization in many regards, and there are many questionnaires that collect somatic symptom counts as a surrogate for this construct

1. Wolfe et. al. Arthritis Rheum. Jun 15 2009;61(6):715-716. 2. Wolfe et. al. J Rheumatol. Feb 1 2011. 3. Clauw DJ. JAMA. 2014.

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Concept of "Fibromyalgia-ness"

Fibromyalgia Symptoms (Modified ACR 2010 Fibromyalgia Diagnostic Criteria)

1. Please indicate below if you have had pain or tenderness over the past 3 months in each of the areas listed below. Check the box in the column below for each area in which you have had pain or tenderness. Be sure to mark right and left sides separately.

2. Using the following scale, indicate for each item your severity over the past week by checking the appropriate box.

No problem
Mild or mild problems, generally mild or intermittent
Moderate, considerable problems, often present and/or at a moderate level
Severe, continuous, life-disturbing problems

	No problem	Mild or mild	Moderate	Severe
a. Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Trouble thinking or remembering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Waking up tired (unrefreshed)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. During the past 6 months have you had any of the following symptoms?	No	Yes		
a. Pain or stings in lower abdomen	<input type="checkbox"/>	<input type="checkbox"/>		
b. Depression	<input type="checkbox"/>	<input type="checkbox"/>		
c. Headache	<input type="checkbox"/>	<input type="checkbox"/>		
4. Have the symptoms in questions 2-3 and pain been present at a similar level for at least 3 months?	No	Yes		
5. Do you have a disorder that would otherwise explain the pain?	No	Yes		

1. Wolfe et. al. Arthritis Rheum. Jun 15 2009;61(6):715-716. 2. Wolfe et. al. J Rheumatol. Feb 1 2011. 3. Clauw DJ. JAMA. 2014.

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From fibrositis to fibromyalgia to nociplastic pain: how rheumatology helped get us here and where do we go from here?

Daniel J. Clauw

Abstract

Nociplastic pain is a mechanistic term used to describe pain that arises or is maintained by altered nociception, despite the absence of tissue damage. Although nociplastic pain has distinct pathophysiology, it overlaps with and is often confused by other pain conditions such as fibromyalgia, irritable bowel syndrome, and chronic fatigue syndrome. This review summarizes the field's current clinical presentation and treatment of nociplastic pain, and discusses how these disorders fit into the broader context of chronic pain. This article concludes with a discussion of the proposed subtypes of nociplastic pain that reflect distinct neurobiology of features and mechanisms.

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- Deployment to war
- Trauma/maltreatment
- Motor vehicle accidents ("whiplash")
- Infections
- As a co-morbidity in individuals with other pain mechanisms (secondary pain)
 - autoimmune disorders (approximately 1/3)
 - sickle cell disease
 - hypermobility syndromes

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- 34

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MANAGEMENT STRATEGIES FOR FATIGUE IN LUPUS

Julius Birnbaum, MD/MHS
Associate Professor, University of Pittsburgh Medical Center (UPMC)
Division Chief, Rheumatology, Mercy Hospital at UPMC
Author of Book: "Living Well With Autoimmune Diseases"

DISCLOSURES

I have no relevant financial relationship(s) with ineligible companies to disclose

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Objectives

- (1) Describe how to identify fatigue in lupus
- (2) Consider how fatigue can be due to non-lupus causes
- (3) Understand that fatigue is usually not associated with active inflammation
- (4) Develop a personalized treatment plan for fatigue
- (5) Explore implications for managing fatigue in other autoimmune disorders

Introduction to fatigue in lupus

Fatigue is the most common symptom in lupus patients!
Occurring in about 90% of patients
In addition, about 50% of lupus patients feel that fatigue is the most disabling symptom
Despite this, patients can feel that it is difficult to describe fatigue in ways that physicians can appreciate

Zorana-Nacachet et al. 2000
Krupp et al. 1989

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Step 1: How I evaluate and define fatigue in lupus patients

Evaluating fatigue is different from other complications of lupus

When asking about other lupus symptoms, simple "Yes or No" responses might be sufficient
In contrast, asking if you have fatigue can only be viewed as a starting point!
Fatigue includes a wide variety of symptoms and differs between individuals
Questions should focus on how fatigue impairs your day-to-day quality of life
Questions should evaluate for the "mental" and "physical" features of fatigue

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Asking about fatigue is only the starting point

Questions should focus on how fatigue is impairing your day-to-day quality of life

Such questions provide meaningful opportunities for your physician to understand your unique experiences of fatigue

Questions should focus on the mental and physical features of fatigue

Mertzet et al, 2020

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Some questions which explore the “physical” components of fatigue

Does fatigue prevent you from starting certain tasks and activities?

Does fatigue make it difficult to carry out job responsibilities?

Does fatigue prevent you from activities that bring you enjoyment?

Does fatigue make it difficult for you to exercise?

How many hours of sleep do you get on a nightly basis?

Do you feel refreshed when you wake up?

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Some questions which explore the “mental” components of fatigue

Does fatigue make it difficult to carry on a conversation?

Does fatigue make it difficult to remember things?

Does fatigue cause you to feel sad, hopeless or frustrated?

Does fatigue make it difficult to remember to take your medications?

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Take-home points about the evaluation of fatigue in lupus patients

Each lupus patient may experience fatigue in many different and individualized ways

Asking about fatigue is so much more than a “Yes or No” experience

Questions need to consider how physical and mental components of fatigue are impairing your day-to-day quality of life

Take-home message: Physicians need to listen to your voice and how you describe such symptoms in unique and individualized ways!

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Step 2: How I identify non-lupus causes of fatigue

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Five non-lupus causes of fatigue

Non lupus causes and testing	Comments
(1) Hypothyroidism testing (all patients)	Cold intolerance, pain, constipation, dry-skin, low heart rate
(2) Vitamin D deficiency (all patients)	Not just high-risk (avoiding sun light)
(3) Chronic adrenal insufficiency that can occur steroid tapering	Pain, nausea, vomiting, muscle weakness
(4) Medications	Treatment of anxiety, allergies, pain
(5) Anemia (iron deficiency, vitamin B12)	Need to ask why iron deficient

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Cancer

A very infrequent cause of fatigue!

Screening for breast, colorectal, cervical, lung, possibly prostate cancer

Consider additional testing if fatigue associated with unexplained weight loss, night-sweats, elevated markers of inflammation (sometimes), abnormal labs

You and your physicians need to decide when even additional studies might be necessary (i.e., CAT scan of chest/abdomen/pelvis).

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Fibromyalgia is more than just a pain syndrome

Chronic widespread pain

Associated with “brain fog” and unrefreshed sleep

Also associated with distressing “somatic” symptoms without a cause

Examples include migraines, ringing in ears, irritable bowel disease

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Take home point: Fatigue can be due to non-lupus causes

Your physician needs to comprehensively search for non-lupus causes

Identification of non-lupus causes can gratifyingly lead to effective treatment!

Be aware that you might have both lupus and non-lupus causes of fatigue

If non-lupus causes excluded, what is relationship between fatigue and lupus?

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Step 3: Is fatigue associated with inflammation?

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Relationship between fatigue and inflammation

Traditional assumption is that fatigue is associated with inflammation

Fatigue is infrequently associated with disease flares

In most cases, fatigue is not primarily associated with disease activity!

Instead, fatigue is mainly associated with non-inflammatory disorders such as fibromyalgia, brain fog, and emotional health concerns such as anxiety or depression

Helpful to understand concepts of type 1 and type 2 lupus

Escola et al, 2023

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Fatigue is more associated with “type 2” as opposed to “type 1” lupus

Important features	Type 1 lupus	Type 2 lupus
Fatigue	Less frequently	More frequently
Active inflammation	More frequently	Less frequently
Evidence of active organ inflammation	More frequently	Less frequently
Examples of organ inflammation	Rash, arthritis, mouth sores, pleuritis, kidney disease	N/A

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Disease is more associated with “type 2” as opposed to “type 1” lupus

Important associated features	Type 1 lupus	Type 2 lupus
Fatigue	No	Yes
Depression	No	Yes
Anxiety	No	Yes
Fibromyalgia and chronic pain	No	Yes
Brain fog	No	Yes

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Fibromyalgia: More than just a chronic pain disorder

Chronic widespread pain

Associated with fatigue, cognitive dysfunction and mood disorders

Other distressing “somatic” symptoms without explanation

Headaches, ringing in ears, irritable bowel syndrome

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Take home point: Fatigue is not usually associated with active disease inflammation

Infrequently associated with inflammation (i.e., flares)

Instead, fatigue is usually associated with type 2 disease which is not associated with inflammation

Treatment of type 2 disease (mood disorders, pain, sleep disturbances) can help with treatment of fatigue

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Step 4: What are some medicinal and non-medicinal approaches I use to treat fatigue in lupus

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Recognize and treat non-lupus causes of fatigue

Treat hypothyroidism

Limit use or dose of medications that may cause fatigue (i.e., sedatives)

Treat anemia not due to lupus (i.e., iron-deficiency)

Treat vitamin D deficiency to target 25-hydroxy vitamin D levels (blood test) at 40-50 ng/mL

Lima GL et al. Arthritis Care Research 2016

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Limited role of immunotherapy in treatment of lupus fatigue

All lupus patients should be on hydroxychloroquine

Corticosteroids and/or immunosuppression will help only if fatigue is associated with inflammation (infrequently)

In most cases management of lupus fatigue is non-inflammatory and will not require immunosuppressive therapy (frequently)

Involves treating chronic pain (fibromyalgia), promoting emotional health, optimizing sleep, obtaining sufficient exercise, and having a healthy diet

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Treatment of fibromyalgia

Optimizing sleep, exercise, and meditation

There are different medications that can be used (don't try to memorize!)

Examples include amitriptyline, duloxetine, milnacipran, gabapentin, pregabalin

More relevant point is discussing with your physician when to start medications and which medicines might be optimal for you

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Taking charge of your emotional health

Anxiety or depression is often deprioritized, but often needs to come at the forefront of the visit

Depression causes features that just as broad as lupus complications

Patients have appetite changes, poor sleep, withdraw from family support and pleasurable activities

Avoid stigma that fatigue is not "real" or "in your head"

Treatment that improves your emotional health can greatly improve fatigue!

Lu et al., 2024

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Sleep strategies

Try to get at least eight hours of sleep per night

At least one hour before bed, try to limit activities that cause suboptimal sleep and can promote a healthy sleep-wake cycles (circadian rhythm)

Turning off cell phones, television and laptops

Avoiding caffeine after lunch

Use preferred sleep-promoting activities (reading, warm baths, yoga or meditation)

Diagnosis and treatment of sleep apnea

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Exercise

Contributes to weight loss, can help treat depression and anxiety, can treat brain fog, and ensure healthy sleep

Can start with walks or running, especially in preferred location

Water aerobics or swimming can be soothing, promote a whole-body workout, and can be used if severe joint pain

Over time, aim for 20-30 minutes a day, enough to have an "aerobic" workout (increase heart rate so that you become sweaty)

Consult with your physician if you have heart or lung disease

Tench et al., 2023

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Dietary strategies

Limit intake of red meat and food that is highly processed, fried or salty

Increase intake of foods that are likely anti-inflammatory and can help manage fatigue

Fruits and vegetables that have a broad range of colors

Examples include berries, grapes, cherries, citrus fruits, leafy greens (kale, spinach, collards), broccoli, mushrooms

Foods rich in omega-3 fatty acids that are likely anti-inflammatory

Include fish (salmon or tuna), nuts (walnuts), seeds (flax seeds) and vegetable oils

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Take home points of this talk

Fatigue can stem from non-lupus causes

All patients should be on hydroxychloroquine and have adequate vitamin D levels

Limited role for immunotherapy since fatigue is usually associated with non-inflammatory causes

Therefore, non-medicinal strategies have a very important role!

Such strategies include treating pain, promoting emotional health, optimizing sleep, obtaining sufficient exercise, and having a healthy diet

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Understanding lupus fatigue and other autoimmune diseases

Lupus fatigue is fascinatingly relevant to other autoimmune diseases!

Fatigue is also frequent in Sjogren's disease and rheumatoid arthritis (RA)

Similar to lupus, fatigue in RA and Sjogren's disease is frequently associated with non-inflammatory features (fibromyalgia, brain fog, depression)

Therefore, these non-medicinal approaches to managing lupus fatigue are highly effective in *any* autoimmune disorder

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"Living Well With Autoimmune Diseases: A Rheumatologist' Guide to Taking Charge of Your Health"

My book includes chapters on lupus and many other rheumatic disorders

As shown in lupus fatigue, "no autoimmune disease is an island."

Chapters also on wellness including fibromyalgia, depression, diet

Unifying theme is patient empowerment!

Further explore at juliusbirnbaum.com

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Questions + Answers

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Contact Us!

202.349.1155

info@lupus.org

Lupus.org

@LupusFoundationofAmerica

@Lupusorg

@Lupusorg

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QR Code

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Thank you for attending!

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